

## **Dementia, Identity, and the Role of Twitter**

Submitted by Catherine Talbot to the University of Exeter  
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Doctor of Philosophy in Medical Studies  
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Signature: .....

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## **Abstract**

The narratives of people with dementia have traditionally been underrepresented in research, policy, and public life. The social networking site Twitter has the potential to affect the lived experiences of people with dementia and facilitate their social inclusion, but research is limited. The overarching aim of this thesis was to explore how and why people with dementia use Twitter. Study One was a content analysis of the profile descriptions of account holders who identified themselves as having dementia. The aims were to identify how many Twitter account holders identified themselves as having dementia, and to examine their characteristics. Study Two was a thematic analysis of the tweets of people with dementia. The aims were to explore how they used Twitter and to examine the illness narratives they created and promoted online. Study Three comprised thematic and longitudinal analyses of case studies of people with dementia. The aims were to examine, in their own words, how and why people with dementia used Twitter, and to explore how this changed over time. The findings of this thesis showed that people with dementia used Twitter to present themselves and their diagnosis in a positive manner. People with dementia used Twitter to have a voice on the issues that affect them, create social change, educate others, establish new social connections, expand existing offline social networks, access peer support, document experiences, communicate, and enhance feelings of self-worth. While the use of Twitter by people with dementia was largely positive, they also experienced technical difficulties, were vulnerable to online abuse, and found the platform increasingly difficult to use as the symptoms of dementia progressed. At present, Twitter might only be appropriate for people in the earlier stages of dementia. In the future, researchers could work with platform developers to make Twitter more dementia-friendly, develop guidelines for people with dementia

on how to use and be safe on Twitter, and use longer timeframes to further examine how the use of Twitter by people with dementia changes as symptoms progress.

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## **Author's Declaration**

Chapters 3-6 are presented as journal articles that have been published or have been prepared for submission to journals. I was responsible for the conception and design of each study, and for gaining ethical clearance to conduct these studies. All three of my supervisors provided critical input on these tasks. This declaration outlines my contribution to each paper, and the contributions of my co-authors.

### **Identifying People with Dementia on Twitter**

In Study One, I was responsible for the collection of Twitter data. Joel Anderson provided critical input on this task. I liaised with the patient and public involvement group to identify search terms. Siobhan O'Dwyer, Linda Clare, and Janet Heaton provided critical feedback on the search strategy. I systematically searched the tweets to identify account holders who identified themselves as having dementia and conducted the content analysis. All four co-authors provided critical feedback on the analysis, including conceptual suggestions for the interpretation. I drafted the manuscript and all of the co-authors provided critical revisions on drafts of the paper.

### **How People with Dementia use Twitter: A Qualitative Analysis**

In Study Two, I sampled the account holders and collected tweets from their profiles. Joel Anderson provided critical input on this task. I conducted the thematic analysis of tweets. I generated the initial codes, coded all of the data, and developed the initial themes. Siobhan O'Dwyer reviewed a sample of coded tweets and reviewed the initial themes. I made amendments where appropriate, and Siobhan O'Dwyer, Linda Clare, and Janet Heaton provided conceptual feedback on the revised themes. I revised the themes until finalised versions of the themes were agreed upon by all of the co-authors. I discussed the themes with the patient and public involvement group who advised on this research. I was also responsible for writing the manuscript, which was reviewed and edited by all four co-authors.

### **The Experiences of People with Young-onset Dementia who use Twitter: A Thematic Analysis**

In this study, I was responsible for recruiting participants. I conducted all of the interviews and administered the measures of cognition and functional ability. I also

transcribed a proportion of the interviews and conducted the thematic analysis. Siobhan O'Dwyer, Linda Clare, and Janet Heaton reviewed a proportion of the anonymised interview transcripts and provided initial coding recommendations. I coded all of the data and identified the initial themes. All three co-authors reviewed and provided conceptual feedback on the initial themes. I made revisions to the analysis where appropriate and generated the finalised themes. I discussed the finalised themes with members of the patient and public involvement group who advised on my research. I drafted the manuscript, with critical revisions provided by all three co-authors.

### **Changes in the use of Twitter by People with Young-onset Dementia: A Longitudinal Analysis**

In this study, I was responsible for recruiting participants and conducting all of the interviews. I also administered the measures of cognition and functional ability, and collected the tweet frequency data. I conducted the recurrent cross-sectional analysis, which included generating initial codes, coding the data, creating the time-ordered matrices, coding the time-ordered matrices, generating longitudinal themes, and creating longitudinal matrices. I also conducted the descriptive analyses of Twitter data and measures of cognition and functional ability. Siobhan O'Dwyer, Linda Clare, and Janet Heaton provided conceptual feedback on the coding and reviewed the analysis. I was responsible for writing the paper, with critical revisions provided by all three co-authors.

# **Chapter 1**

## **Introduction**



## 1.1 Dementia

Dementia refers to a set of symptoms, produced by a number of different conditions in which there is progressive cognitive decline, and functional impairments that impact daily life (McKeith et al. 2017; McKhann et al. 2011). A person is diagnosed with dementia when: (1) there is evidence of significant cognitive decline in one or more cognitive domains, such as learning and memory, language, executive function, complex attention, perceptual-motor ability, or social cognition; (2) the cognitive or behavioural symptoms interfere with daily life; (3) the symptoms do not exclusively occur during a period of delirium; and (4) the symptoms cannot be explained by another psychiatric disorder (American Psychiatric Association, 2013). People who experience symptoms of dementia before the age of 65 are described as having young-onset dementia (Lambert et al. 2014). Young-onset dementia is less common than late-onset with approximately 5% of people with dementia diagnosed before the age of 65 (Prince et al. 2014). Alzheimer's disease (62%) is the most common type of dementia, followed by vascular dementia (17%), mixed dementia (10%), dementia with Lewy bodies (4%), and frontotemporal dementia (2%; Prince et al. 2014).

Alzheimer's disease is characterised in its early stages by impairments in episodic memory (Sheikh-Bahaei, Ahmad Sajjadi, & Pierce, 2017). These impairments are associated with neurofibrillary tangles and amyloid- $\beta$  plaques contributing to neurodegeneration, particularly in the hippocampus (Ossenkoppele et al. 2015). Atypical variants of Alzheimer's disease, such as posterior cortical atrophy, are diagnosed when the first symptoms of dementia are not memory loss. Posterior Cortical Atrophy, for example, is characterised by perceptual difficulties in the early stages (Wolk, 2013).

Other types of dementia have different clinical profiles. People with behavioural variant frontotemporal dementia may exhibit changes in personality, interpersonal conduct, and emotion (Piguet, Kumfor, & Hodges, 2017), whereas semantic dementia is characterised by a loss of conceptual knowledge (Landin-Romero, Tan, Hodges, & Kumfor, 2016). People with Lewy body dementia may experience visual hallucinations, fluctuating cognition, spontaneous features of Parkinson's disease, and rapid eye movement sleep behaviour disorder, which is associated with the formation of Lewy bodies in the brainstem, limbic, and neocortical areas of the brain (McKeith et al. 2017; McKeith & Mosimann, 2004).

The impact of dementia, however, is not exclusively neurological. The effects of dementia result from complex interplay between the neurological, social, and psychological factors that shape experience. The following section explores these factors, with a particular focus on identity.

## **1.2 Identity**

A diagnostic label of dementia can have a powerful impact on a person's identity (Bunn et al. 2012), where identity is "the individual's knowledge that he [/she] belongs to certain social groups together with some emotional significance to him [/her] of the group membership" (Hogg & Abrams, 1988, p7). Burke (1980) theorised that identity is relational, social, and placed in a context of interaction. In this sense, identity is not static, but is reconstructed through social interaction.

A diagnosis of dementia can negatively affect a person's sense of identity, resulting in feelings of loss, anger, uncertainty, and frustration (Beard & Fox, 2008; Langdon, Eagle, & Warner, 2007). The diagnosis can result in diminished power in

relationships, fewer social roles, and fewer positive social interactions (Ryan, Bannister, & Anas, 2009). People with dementia have also experienced stigmatisation, a loss of social contacts, and a 'shrinking world' after receiving a diagnosis (Duggan, Blackman, Martyr, & van Schaik, 2008; Spreadbury & Kipps, 2019; Swaffer, 2014).

The diagnosis can be particularly challenging for people with young-onset dementia because they tend to have greater financial commitments, younger children, and still be working at the time of diagnosis (Johannessen & Möller, 2010; Roach & Drummond, 2014). Researchers have also found that some people with young-onset dementia experience a loss of purpose following diagnosis, resulting from being unable to work or take part in certain activities (Roach & Drummond, 2014).

### **1.3 Theoretical Background: Identity as Narrative**

Qualitative researchers have used varying approaches and concepts to examine identity in dementia research. In a systematic review of the research on identity and selfhood in dementia, Caddell and Clare (2010) found that qualitative researchers used social constructionist (e.g. Li & Orleans, 2002; Sabat & Collins, 1999; Sabat, 2002), interactionist (e.g. Hubbard, Cook, Tester, & Downs, 2002; Saunders, 1998), embodied selfhood (e.g. Kontos, 2004), and narrative models of identity (e.g. Mills, 1997; Surr, 2006; Usita, Hyman, & Herman, 1998). This early research was primarily conducted to examine to what extent identity persists among people with dementia. Although some of these studies highlighted the losses that some people with

dementia may experience, the majority suggested that identity is preserved to some degree in both the mild and moderate to severe stages of dementia.

A narrative model of identity is the theoretical approach underpinning this thesis. A narrative approach examines identity through the personal narratives of people with dementia (Baldwin et al. 2008). Researchers have theorised that the process of narrative construction allows people with dementia to preserve, update, and define their identity (Mills, 1997; Ryan et al. 2009; Surr, 2006; Usita et al. 1998). This 'identity as narrative' approach has been criticised for being limited to people with dementia who are able to communicate (Caddell & Clare, 2010); however, researchers have demonstrated that people in the moderate to severe stages of dementia are also able to construct narratives to some degree (Mills, 1997; Surr, 2006; Usita et al. 1998).

Narrative identity is constructed through the stories that people communicate about their experiences, and is therefore associated with illness narratives, which refer to stories told by individuals about their experiences of disease or disability (Garden, 2010; Hydén, 1997). These stories are expressed using the person's own voice where he or she is the central character who experiences the illness, rather than simply the disease pathology itself (Sakalys, 2003; Vanderford, Jenks, & Sharf, 1997). Illness narratives have extended discussions of health beyond the biomedical perspective to encompass the meaning that people ascribe to their illness or disability, and the influence it has on their roles, relationships, and identities (Garden, 2015). Written narratives can be particularly beneficial for people with health conditions and disabilities, as it provides them with an increased level of empowerment over the stories they wish to communicate (Ryan et al. 2009; Ryan, Spykerman, & Anas, 2005). Illness narratives have provided a medium of

communication through which people with health conditions or disabilities can reconstruct and communicate their identity to other people.

Baldwin and colleagues (2008) theorised that narrative is performative, and this activity requires agency and opportunity, which people with dementia have traditionally been denied. In fact, the narratives of people with dementia have traditionally been underrepresented in research, policy, and public life. The following section outlines early understandings of dementia, the emergence of dementia narratives, and the changing identities of people with dementia over time.

## **1.4 The Changing Identities of People with Dementia: From Sufferers to Advocates**

### **1.4.1 Early understandings**

The historical model for understanding dementia has been the medical model of cognitive deficit, which focused on dementia as a solely neurological condition (Baldwin et al. 2008). People with dementia were seen as 'diseased brains', rather than human beings who experience the world (Cheston & Bender, 1999). It was previously assumed that the disease pathology prevented those with dementia from articulating their perspectives in a meaningful way, being believed to be irrational and unable to communicate (Brown & Zavestoski, 2004). In addition, a lack of awareness about changes or difficulties associated with the onset and progression of dementia was also assumed to be a symptom of dementia (e.g. Feher, Mahurin, Inbody, Crook, & Pirozzolo, 1991). Consequently, beliefs about the symptoms of dementia during this time invalidated the perspectives of people with dementia.

Dementia was understood in terms of loss, whereby people with dementia were assumed to experience a loss of identity, mental capacity, abilities, and meaningful experiences (Davis, 2004; Downs, 1997; Moore & Hollett, 2003; Sabat, Johnson, Swarbrick, & Keady, 2011). People with dementia were identified as patients and victims (e.g. Fontana & Smith, 1989), who experienced a loss of self (e.g. Cohen & Eisdorfer, 1986) and faced a living death as the disease progressed (e.g. Woods, 1989). The perceived loss of identity in people with dementia was accompanied by a loss of agency and citizenship status, whereby people with dementia were not given the status of complete people (McParland, Kelly, & Innes, 2017). Early understandings of dementia and beliefs about the condition contributed to the marginalisation and dehumanisation of people with dementia. This prevented people with dementia from communicating their experiences, denying them their rights to self-affirmation and self-assertion (Behuniak, 2010; Wilkinson, 2002).

#### **1.4.2 Changing perspectives**

Understandings of dementia started to change in the late twentieth century, when an emphasis was placed on early diagnosis. The first memory clinic in the UK was established in 1983 with the aim of detecting dementia during the early stages (Van der Cammen, Simpson, Fraser, Preker, & Exton-Smith, 1987; Wright & Lindesay, 1995). Following this, the number of memory clinics increased substantially from 20 in 1993 to 102 in 2000 after the licensing of the first symptomatic drug treatment for Alzheimer's disease, Donepezil, in 1997 (Wright & Lindesay, 1995; Lindesay, Marudkar, van Diepen, & Wilcock, 2002). This increase meant that people were diagnosed during the earlier stages of dementia and, therefore, more likely to be able to communicate their experiences.

A person-centred approach to dementia also emerged in the late 1980s and 1990s. This approach moved beyond the tendency to view dementia solely within a medical framework, and emphasised the importance of the social situation and lived experience. The work of Thomas Kitwood (1987, 1990, 1993, 1997; Kitwood & Bredin, 1992) was highly influential in this movement and highlighted the malignant treatment of people with dementia by healthy others. Central to this movement was the acknowledgement of personhood in people with dementia, where personhood refers to “the standing or status that is bestowed on one human being, by another in the context of a relationship and social being” (Kitwood, 1997, p8). Kitwood theorised that the social situation in which people with dementia were treated and cared for influenced their lived experiences, whereby the label of dementia restricted those with a diagnosis to a limited range of social roles through which all future behaviour was interpreted (Kitwood & Bredin, 1992). For Kitwood, people with dementia were not only disadvantaged by the disease, but also the actions and attitudes of other people.

The influence of the social situation was also highlighted by Sabat and Harré (1992) who suggested people with dementia were vulnerable to malignant positioning by healthy others who positioned them as a ‘patients’ or ‘sufferers’, causing them to withdraw from other social roles. These social models of dementia identified the social situation to be disabling, rather than locating the problem within the person, and emphasised the importance of the social situation. These models were pivotal in creating space for people with dementia to share their perspectives.

### **1.4.3 Qualitative research**

Qualitative research conducted with people with dementia developed from social models of dementia. Goldsmith (1996) wrote a highly influential book promoting the idea of listening to the voices of people with dementia, which was radical at the time. In line with this, researchers conducted qualitative research with people with dementia, thus recognising the value of their perspectives (e.g. Clare, 2002a; Pearce, Clare, & Pistrang, 2002; Sabat, 2002).

Through their use of qualitative methods, researchers challenged previous assumptions about the symptoms and abilities of people with dementia. Clare (2002b, 2003), for example, conducted interviews with people with early-stage Alzheimer's disease and found that all participants were able to acknowledge their memory problems, therefore demonstrating a basic awareness of changes in cognition. She also highlighted other psychological (e.g. coping mechanisms) and social (e.g. social networks) factors that could contribute to unawareness, concluding that in many cases, unawareness could be viewed as the product of psychosocial processes, which interact with cognitive impairments. This early research challenged previous beliefs that unawareness was a symptom of dementia and highlighted the importance of psychological and social factors.

The early qualitative research taking place in the 1990s and early 2000s demonstrated that people with dementia were able to participate in qualitative studies and respond to open-ended questions in a meaningful way (Moore & Hollett, 2003), which challenged previous assumptions about the abilities of people with dementia. This highlighted that research guided by a social understanding of dementia could be used to gain insight into the experiences of people with dementia beyond those provided by proxy medical report (Wilkinson, 2002).



Following this, an increasing number of researchers recognised the importance of engaging with people with dementia, in which research should be conducted *with* people with dementia, rather than *on* them. Wilkinson (2002), for example, highlighted that only by speaking to people with dementia can researchers gain accurate insight into their experiences, wants, and needs. Not engaging with the voices of people living with dementia could result in a lack of understanding, which could ultimately result in inadequate care.

The shift from a purely medicalised view of dementia towards a social understanding of dementia signals an increased recognition of people with dementia as people with experiences and perspectives worth listening to (Bartlett & O'Connor, 2007). Consistent with this, a growing number of researchers included the voices of people with dementia in research and acknowledged their individual experiences, as well as their rights and perspectives, rather than just their neurobiology (e.g. Benbow & Kingston, 2016; Górska, Forsyth, & Maciver, 2017; Hillman, Jones, Quinn, Nelis, & Clare, 2018; Read, Toye, & Wynaden, 2017; Toms, Quinn, Anderson & Clare, 2015). An increased recognition of the importance of lived experience identified people with dementia as service users, consumers, and people who could live with dementia.

#### **1.4.4 Narratives of people with dementia**

As well as having their perspectives presented by researchers, people with dementia have communicated their own perspectives in which they, crucially, controlled the narrative. The illness narratives of people with dementia started to slowly emerge in the late 1980s and 1990s. Among the earliest of these, Davis (1989) described his experiences of having Alzheimer's disease and the impact it had on his career, marriage, and confidence. Subsequently, more autobiographies

written by people with dementia were published in the 1990s, such as 'Living in the Labyrinth' (McGowin, 1993) and 'Show me the Way to go Home' (Rose, 1996). In these early illness narratives, the authors communicated their experiences of dementia; their feelings of embarrassment, frustration, and anger (Downs, 1997); and a desire for inclusion and support (Moore & Hollett, 2003). Importantly, these early illness narratives demonstrated that people with dementia were able to communicate their experiences in a coherent manner, which contrasted with previous assumptions about their abilities.

An increasing number of dementia narratives were published in the late 1990s and early 2000s. These narratives focused on communicating the unique experiences of people with dementia and challenging common misconceptions. Snyder's (1999) book 'Speaking our Minds: Personal Reflections from Individuals with Alzheimer's' documented the stories of seven people with dementia. This book emphasised the unique experience of each person, demonstrated how people with dementia are forced to redefine themselves following a diagnosis, and highlighted what endures in each person. Likewise, in Bryden's (2005) book "Dancing with Dementia: My Story of Living Positively with Dementia" she challenged common beliefs about dementia and demonstrated a continued identity, despite her diagnosis.

These narratives emphasised that people with dementia could live with the condition and communicate their experiences in a meaningful way, thus positioning themselves as appropriate advocates. By communicating their perspectives in this way, people with dementia were able to explore a new positive identity with dementia and engage in a social dialogue that challenged stereotypical assumptions, thereby affirming their identities as people who can live with the condition (Ryan et al. 2009),

and moving beyond traditional *suffering* and *living death* narratives (e.g. Fontana & Smith, 1989; Woods, 1989).

#### **1.4.5 Dementia advocacy**

With growing recognition of the importance of lived experience, a focus on early diagnosis, and the emergence of dementia narratives, people with dementia started to advocate for themselves. These advocates rejected approaches that framed them as sufferers or passive patients, and adopted a ‘nothing about us without us’ paradigm (Thomas & Milligan, 2018).

The Alzheimer’s Society Research Network was established in 1999 with the aim of developing a network of people with dementia and their carers who could be involved in determining the Alzheimer’s Society’s Research programme (Alzheimer’s Society, n.d.). Research Network volunteers were able to contribute valuable insight into the design and delivery of research, and influence dementia research funding at a national level. More recently, members of the network have commented on grant applications, supported research, sat on steering groups, and acted as co-applicants on research applications.

The Dementia Advocacy and Support Network International (DASNI) was instrumental in advocating for the inclusion of people with dementia in the discussions that concerned them (Beard, Knauss, & Moyer, 2009). DASNI was an internet-based self-help and mutual support network for people with dementia, which was established in 2000. In research that was collaboratively conceived and planned with DASNI members, Clare, Rowlands, and Quin (2008) reported that DASNI membership produced a strong sense of collective strength, which lessened the feelings of isolation and loneliness among DASNI members. A key focus of DASNI

was to empower people with dementia to become actively involved in their own care and treatment, and to improve the lives of others by speaking out (Batsch & Mittelman, 2012). DASNI not only allowed people with dementia to connect with one another but enabled them to actively campaign for their citizenship rights (Birt, Poland, Csipke, & Charlesworth, 2017; Clare et al. 2008).

In 2001, DASNI member Christine Bryden became the first person to speak about her diagnosis at the Alzheimer's Disease International (ADI) conference. Following this, the inclusion of people with dementia became an essential feature of the conference. In 2003, Bryden became the first person with dementia to be elected to the ADI board of directors. This role allowed Bryden to share her perspectives with a prominent organisation and, in turn, increased the likelihood of influencing policy making (Gilmour & Brannelly, 2010). Other dementia advocates have taken active roles in the work of other Alzheimer's associations worldwide (Beard, 2004), educated medical and applied health students about their lived experiences (Hope, Pulsford, Thompson, Capstick, & Heyward, 2007), and engaged with researchers and professionals to help shape research and practice (e.g. Litherland et al. 2018).

Over the past 20 years, an increasing number of dementia working groups have been established that advocate for the rights of people with dementia. The Scottish Dementia Working Group (SDWG), for example, was formed in 2002 as a national campaigning group ran by people with dementia, which aimed to influence public policy and attitudes about dementia in Scotland (Weeks, Wilkinson, Houston, & Mckillop, 2012). The European Working Group of People with Dementia and the Three Nations Dementia Working Group were recently established to influence research, practice, and policy making in Europe, Northern Ireland, and Wales, respectively. Likewise, Dementia Action Alliance was launched in 2014, which is the

global advocacy group for people with dementia. Through their collective action and communication of lived experience, people with dementia have challenged traditional assumptions of dementia, impacted upon the practices and policies that affect their lives, and contributed to a greater social and political understanding of dementia.

Researchers have also found that people with dementia may benefit personally from engaging in advocacy. Clare and colleagues (2008), for example, suggested that people with dementia may experience an increased sense of collective identity and self-confidence when they unite and take action. In a qualitative study of people with dementia who engaged in advocacy, Bartlett (2014a) found that participants engaged in advocacy to protect themselves against cognitive decline, to connect with other people with dementia, and to regain respect from themselves and other people. Likewise, in a separate qualitative study, Bartlett (2014b) found campaigning was energising for some people with dementia and reaffirming of their citizen identity because it provided them with a working role.

Despite the potential benefits of advocacy, the participants in Bartlett's (2014b) study experienced fatigue from campaigning. These participants also felt oppressed by the normative expectations from healthy others who were confused when they did not present themselves in a typical way, resulting in feelings of guilt. This finding is reflected in current debates, whereby certain clinicians have questioned the diagnoses of dementia advocates. Howard (2017), for example, doubted the diagnoses of some dementia advocates, suggesting that if they are able to take part in advocacy work, they could not have dementia. While it is true that people can be misdiagnosed with dementia, recent medical policy initiatives (Department Of Health, 2016) have focused on diagnosing people during the earlier stages of the disease.

This has afforded people with dementia more time to live with the condition; consequently, these people are more able to communicate their perspectives.

One key issue is that dementia advocates may not be representative of a typical person with dementia. This was reflected in Bartlett's (2014a) research, which used a relatively homogenous sample consisting of predominantly white, male, younger people with dementia. Consequently, this research did not capture the diversity of experiences of people with dementia, and greater effort is required by researchers to engage with the voices of underrepresented groups, such as women (Ludwin & Parker, 2015), ethnic minorities, LGBTQ+ individuals, and people with rare forms of dementia. The voices of these individuals, their motives for advocacy, and their advocacy activities remain underrepresented in research.

As part of their advocacy work, dementia advocates have communicated their experiences of living with the condition. Swaffer (2016), for example, in 'What the Hell Happened to my Brain' described her experience of living with young-onset dementia, challenged myths about dementia, and called for people with dementia to be included in the decisions that concern them. In her writing, she discussed her advocacy work, suggesting that advocacy helped her to develop a new meaningful identity in the aftermath of receiving her diagnosis. Likewise, in 'Dementia Activist: Fighting for Our Rights', Rohra (2016) challenged dementia stereotypes and discussed her advocacy work. In 'Nothing About us, Without us!', Bryden (2015) promoted self-advocacy and demanded change in the way dementia is perceived. More recently, in 'Somebody I Used to Know', Mitchell (2019) shared her experience of being diagnosed, and her acceptance of a new identity living with dementia. Through these narratives, people with dementia have highlighted the issues that

concern them and reframed their condition as a manageable disability rather than a 'living death' (Beard et al. 2009; Woods, 1989).

The narratives of people with dementia have not been limited to written accounts, and are increasingly including varying types of media. 'Living with Dementia: Chris's Story' (David, 2016), for example, was a BBC documentary that followed Chris Roberts and his family across a period of two years, during which they came to terms with his diagnosis of Alzheimer's disease. The documentary provided the audience with a visual representation of Chris and his family's experience, as well as insights into their emotions, views, and perspectives. Although the documentary was pivotal in communicating the experience of dementia to the general public, it failed to emphasise certain aspects of Chris' narrative such as his advocacy work, suggesting it did not portray all aspects of his identity.

It is clear that there has been an increase in the visibility of the narratives of people with dementia in the past 30 years. The authors of these narratives have confronted dementia stereotypes by documenting their experiences in vivid detail, despite declining cognitive function. It should be remembered, however, that the authors of these illness narratives may not be representative of the wider population of people with dementia. These authors have tended to be younger, well-educated people (McParland et al. 2017). Although the subjective narratives of these people are a powerful source of data on what it is like to live with dementia, they may not reflect the full range of perspectives on this topic.

#### **1.4.6 Citizenship approaches to dementia research**

The emergence of dementia advocacy has been coupled with a rise in citizenship approaches to dementia research. Disability researchers have defined citizenship as a “process of proactive engagement” in society in which “differentials of power” are acknowledged and addressed (Bartlett, 2014b; Beckett, 2005, p405). Citizenship approaches to dementia research have championed the rights and social inclusion of people with dementia (e.g. Bartlett, 2016; Baldwin et al. 2008).

A key difference between a personhood and a citizenship approach is that discussions about citizenship focus on the lack of power that some citizens have in relation to others (Twine, 1994). Bartlett and O'Connor (2007) argued that a citizenship approach has deeper implications than an approach focused on personhood, because it extends conversations into the realm of political discourse, while a personhood approach alone does not necessarily promote people with dementia as having agency.

Citizenship has been important in disability studies, whereby the process of making the personal experiences of discrimination political can improve the experiences of marginalised groups (Campbell & Oliver, 1997; Tregaskis, 2002). Barnes, Auburn, and Lea (2004) suggested that citizenship status is something that individuals achieve through everyday talk and practice, rather than something that is given to them. In this sense, narrative is inherently linked with citizenship (Baldwin et al. 2008). Through these narratives, people with dementia can reposition themselves as citizens, rather than sufferers, and promote their social inclusion.

Despite this progress towards citizenship and ‘nothing about us without us’ models of dementia, traditional forms of narrative such as writing books, speaking at conferences, and appearing on television programmes, are not an option for all



people with dementia. The freely available platforms of social media, however, may provide a more equitable path to advocacy and narrative, but only a few studies have explored this. To understand why social media might be a useful tool for people with dementia, it is first important to define social media and discuss its history.

## **1.5 Social Media**

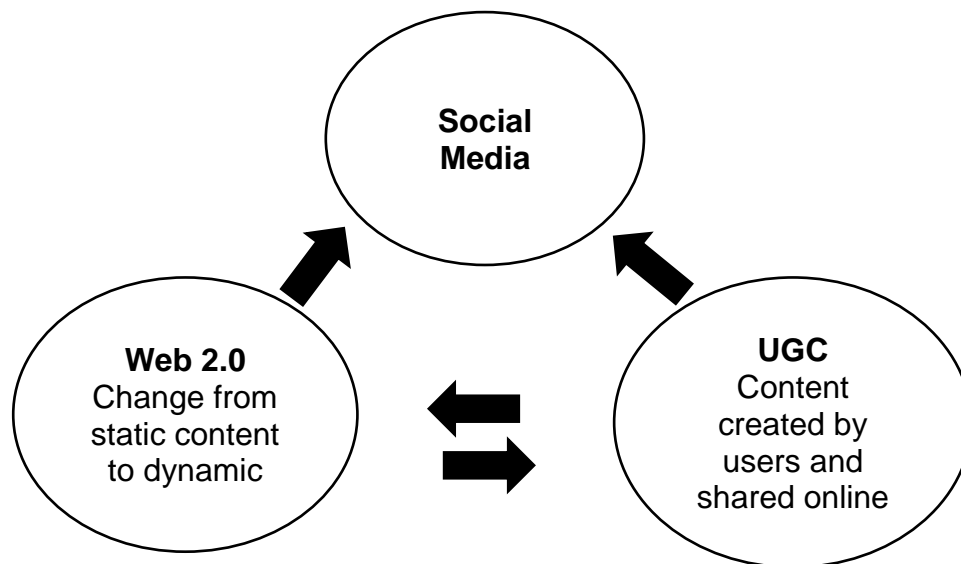
### **1.5.1 A definition of social media**

‘Web 2.0’ and ‘User Generated Content (UGC)’ form the framework of social media, and as such, any definition of social media is reliant upon these two entities. The term Web 2.0 reflects a revolution in the way the web is designed and used (Anderson, Hepworth, Kelly, & Metcalfe, 2007). It refers to a transformation in how software developers and end-users make use of the internet, where content is no longer static (as in Web 1.0), but instead undergoes continuous modification by end-users in a way that is both participatory and collaborative (Kaplan & Haenlein, 2010).

UGC refers to the various forms of media content created by users (Daugherty, Eastin, & Bright, 2008). UGC must satisfy three requirements: the content must be publicly accessible or available to a specific group; there must be evidence of creative effort; and the content must be created outside of professional routines and practices (Vickery & Wunsch-Vincent, 2007). This specification excludes information shared by email or instant message, content that has simply been replicated, and content that has been created solely for the commercial market.

Web 2.0 and UGC are the essential foundations of social media as we know it today (see Figure 1.1). Using these two interrelated concepts, social media can be defined as a group of internet-based applications that advance the ideological and

technological foundations of Web 2.0, and enable the creation and exchange of UGC.



*Figure 1.1.* The relationship between Web 2.0, user-generated content, and social media.

### **1.5.2 A brief history of social media**

Precursors of social media can be traced back to the late 1970s with the development of bulletin board systems and Usenet, a collection of newsgroups where users could post messages, which were then distributed via Usenet servers.

In 1991, the invention of the World Wide Web connected hypertext technologies, a software system allowing extensive cross-referencing between related sections of text and associated graphic material, to the internet. This generated a new approach to networked communication that took place through email, list-servers, and

Weblogs (van Dijck, 2013). The term 'weblog' evolved into blog when bloggers transformed 'weblog' into 'we blog'. Blogs were one of the earliest form of social media and can be defined as web pages that consist of an author's writings about information, opinions, reflections, and personal diary entries (Kaplan & Haenlein, 2010).

Most blogs allow visitors to comment on blog posts (Doctorow, Dornfest, Powers, Johnson, Trott, & Trott, 2002). The ability to comment on a blog facilitates a conversation between the primary author of the blog and secondary comment contributors (Anderson et al. 2007). Blogs, as we know them today, can be traced back to 1998 and 1999 with the launch of Open Diary and LiveJournal, respectively. These blogs brought online diary writers together to construct a collective of individuals who shared an interest in diary writing.

The increased popularity of blogs alongside the increased availability of high-speed internet after the millennium were important precursors to the creation of social networking sites such as MySpace (2003) and Facebook (2004, Harvard only; Kaplan & Haenlein, 2010). Social networking sites are websites that promote interpersonal contact between individuals and/or groups (van Dijck, 2013). Users of social networking sites engage with other users by creating profiles that contain personal information, sharing information with others, and allowing other account holders access to their profiles.

With the technological update of mobile phones to include 3G and 4G internet access, social media have become mobile and more easily accessible as users are no longer restricted to a desktop computer (Ling, 2008; McNab, 2009). A timeline outlining the development of popular social media is illustrated in Figure 1.2.

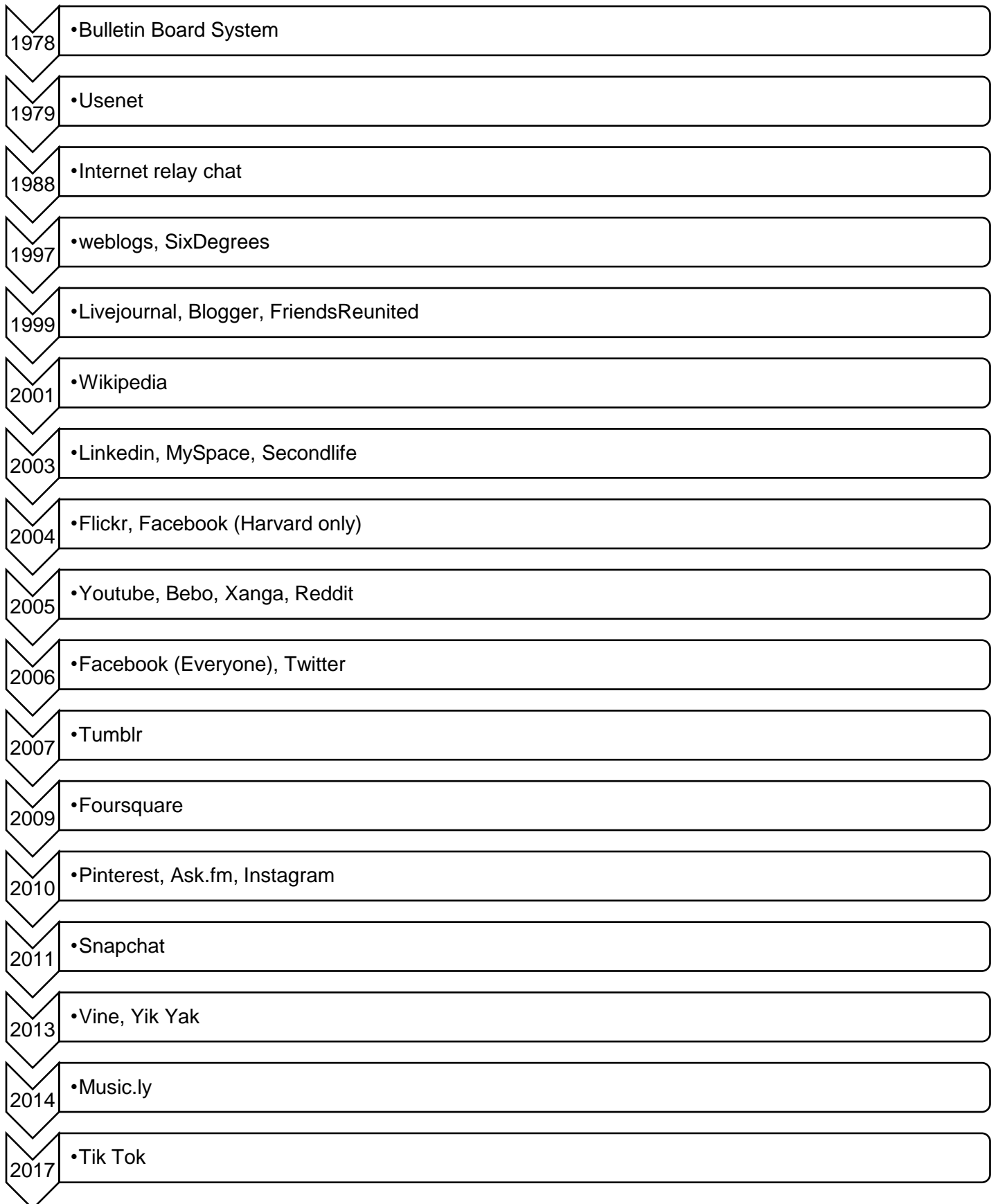


Figure 1.2. The launch dates of popular social media.

### **1.5.3 The use of social media by people with dementia**

In recent years, older adults have become increasingly active on social media. The Pew Research Centre found that the use of social networking sites among people over the age of 65 increased from 13% in 2009 to 40% in 2018 (Smith & Anderson, 2018). While dementia is not a disease of old age, the risk of having dementia increases with age (Baumgart, Snyder, Carillo, Fazio, Kim, & Johns, 2015). It is therefore likely that people with dementia form part of this group of older adults who use social media. Social media could also provide an equitable path to advocacy and narrative for people with dementia, but only a few studies have examined this.

#### **1.5.3.1 Online forums**

The development of social media has allowed communities to emerge and exist online, despite geographical distances. Internet forums refer to online spaces where people can read and post messages to develop a conversational 'thread' (Vayreda & Antaki, 2009). People with chronic health conditions have used internet forums to unite, share their experiences, and provide mutual support (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). People with dementia are among this cohort using online forums (Rodriquez, 2013). In a textual analysis of a forum for people diagnosed with early-onset Alzheimer's disease, Rodriquez (2013) found that forum members shared stories, information, and adaptive strategies, as well as their hopes and fears. By communicating their individual experiences, Rodriquez (2013) argued that people with dementia used online forums to create a sense of community.

Rodriquez (2013) analysed forum posts published between 2008 and 2009. Since then, social media has advanced technologically and increased in popularity. Forums

represent a more static type of social media, whereas recent forms of social media are more interactive and facilitate greater engagement (Kaplan & Haenlein, 2010). In addition, the community studied by Rodriguez was limited to those with a diagnosis of young onset Alzheimer's disease, whereas more popular forms of social media may provide a space for people with different types and stages of dementia.

### **1.5.3.2 Blogs**

As aforementioned, illness narratives were traditionally written on paper or expressed verbally. Blogging refers to the process of online journaling through which people communicate their experiences and perspectives (Leggate, 2012). The advent of social media, and in particular blogging, has provided a digital platform through which illness narratives can be articulated to a wider audience (Heilferty, 2009; Ressler, Bradshaw, Gualtieri, & Chui, 2012). Blogs written by people with dementia might contain important information about the experiences of these individuals, including evidence of the ways in which they affirm their identity.

In contrast with more traditional forms of illness narrative, blogs have the advantage of enabling a continuous process of reconstruction that allows a reader to see how the author's experiences and perspectives change over time (Heilferty, 2009). Blogs tend to be unsolicited and driven by the concerns of individuals, rather than editors or researchers (O'Brien & Clark, 2012). This is particularly important for people with dementia who, through their use of blogging, might be able to communicate their own experiences and, crucially, control the narrative.

Previous research has identified a number of blogs written by people with dementia, which have been used for advocacy and documenting experience (Kannaley, Mehta, Yelton, & Friedman, 2019; Lorenz, Freddolino, Comas-Herrera,

Knapp, & Damant, 2019). In an analysis of blogs written by people with dementia, Kannaley and colleagues (2019) found that people with dementia wrote about the effects of dementia on them and/or their care partner, seeing the positives, feeling out of control, advocacy and empowerment, and coping mechanisms.

The findings of Kannaley and colleagues (2019) suggest that people with dementia have used blogs to document both positive and negative experiences. This contrasts with the traditional illness narrative literature where the dominant narrative focuses on recovery (Garden, 2010), which is reflected in recent dementia autobiographies that emphasise the notion of living well with dementia (e.g. Swaffer, 2016). While these narratives are important for challenging dementia stereotypes and giving hope to those with a diagnosis, it should be remembered that not all people with dementia feel this way and there are some people who find living with dementia very difficult (e.g. Bartlett, Windemuth-Wolfson, Oliver, & Denning, 2017). Blogs and other social networking sites might provide a platform for alternative narratives, including those of people with dementia for whom the term 'living well' does not apply.

Despite the value of blogs to provide insight into the experiences of people with dementia, they require a certain amount of reflection, which some people with dementia might find difficult due to limitations in cognitive capacity. In addition, blogs do not tend to be written during or immediately after an event, and therefore lack the immediacy of other forms of social media, such as Twitter, which could be used by people with dementia to communicate real-time emotions and experiences.

### **1.5.3.3 Facebook**

Popular social networking sites such as Facebook and Twitter could offer people with dementia the opportunity to share their experiences and emotions in real-time, while also providing an important source of social connection. “The Young Onset Dementia Support Group”, for example, is a Facebook group that aims to support people with young-onset dementia by providing them with a platform that they can use to express themselves and communicate with others. This group encourages comments and contributions from people with dementia, identifying these individuals as experts by experience (Craig & Strivens, 2016).

In an evaluation of this Facebook group, Craig and Strivens (2016) found that the group provided members with a unique opportunity for expression, support, and awareness raising. Importantly, members felt the Facebook group allowed people with dementia to connect with others outside of their direct networks, and enabled carers and the general community to engage with their experiences. Many of the people who posted in the Facebook group reported feelings of isolation in daily life, which they associated with changes in their cognition (Craig & Strivens, 2016). Studies of older people without dementia have shown that internet use can be beneficial for older adults in assisted and independent living communities by increasing social connection and decreasing feelings of isolation (Cotton, Anderson, & McCullough, 2013). Social networking sites might also help people with dementia to combat feelings of isolation and loneliness.

Although Craig & Strivens’ (2016) evaluation of the young onset dementia Facebook group provided clear evidence of mainstream social media use by people with dementia, it was limited to people with young-onset dementia. Research that examines the use of social media by people diagnosed later in life is required to



determine whether they use social media differently. In addition, Facebook is only one social networking site and the Young Onset Dementia Support Group is only one group of many. More research is therefore required to examine the use of different social networking sites by people with dementia.

## **1.6 Twitter**

Although Facebook is the most commonly used social networking site (Smith & Anderson, 2018), there are many other popular social networking sites, including Twitter. It has been estimated that people send more than 500 million tweets per day (Stricker, 2014). On Twitter, account holders send short statements, known as 'tweets'. Tweets were originally limited to 140 characters until November 2017 when Twitter increased the character limit to 280 (Rosen & Ihara, 2017). The character limit of tweets could be beneficial for people with dementia to communicate their personal narratives due to difficulties with concentration.

On Twitter, account holders can 'follow' each other so they can see one another's tweets in their 'feed'. It is possible for any account holder to follow any public profile. Consequently, account holders are more likely to connect with people who they have not met offline. Twitter might be particularly useful for people with dementia by providing a platform through which they can connect with people outside of their direct offline networks.

Twitter has also been used to further social movements, challenge social norms, and provide a space for those who have been marginalised to share their perspectives (Highfield, 2016). The hashtag '#BlackLivesMatter', for example, has been used to facilitate discussion about racial inequalities and evoke social change

(Highfield, 2016; Wilkins, Livingstone, & Levine, 2019). Twitter has huge potential for uniting people who share a common goal and it can also be used to give a voice to specific individuals who have been marginalised or ignored offline (Trevisan, 2017). Twitter could be equally valuable for people with dementia to facilitate their social inclusion, providing a platform for people with dementia to communicate their lived experiences and create social change.

### **1.6.1 The use of Twitter by people with chronic health conditions**

A limited amount of research has examined the use of Twitter by people with dementia. In contrast, there has been substantial research on the use of Twitter by people with other chronic illnesses and disabilities. The following section provides an overview of the research on the use of Twitter by people with mental health problems, diabetes, cancer, and communication disabilities, before evaluating the limited amount of dementia-related Twitter research.

#### **1.6.1.1 Mental health**

Recently, researchers have examined how people with mental health problems have used Twitter. Berry, Lobban, Belousov, Emsley, Nenadic, and Bucci (2017) analysed tweets using the hashtag '#WhyWeTweetMH' and found that people tweeted about mental health to foster a sense of community. Twitter allowed people with mental health problems to connect, socialise, share information, tackle stereotypical assumptions, and provide and offer support. Through their use of Twitter, people with mental health problems felt they could connect with others with a shared understanding, thereby reducing feelings of isolation and loneliness.

Likewise, Lachmar and colleagues (2017) found that account holders used the hashtag “#MyDepressionLooksLike” to discuss the cognitive, lifestyle, and social implications of living with depression, as well as their experiences of sadness, seeking relief, hiding their diagnosis, and suicidal thoughts and behaviours.

From these initial analyses, Twitter appears to be providing people the opportunity to speak openly about mental health. An analysis of tweets posted by people with dementia could provide similar insights, including whether people with dementia are using Twitter to openly discuss their symptoms and experiences. The findings of Berry and colleagues (2017) and Lachmar and colleagues (2017) also indicated that Twitter was an important source of social connection for people with mental health problems. This could also be true for people with dementia who often experience feelings of isolation following a diagnosis (Spreadbury & Kipps, 2019).

Although the research described above suggests that Twitter can be a supportive tool for facilitating honest discussions about mental health, it is important to note that the existing studies tend to be weighted towards positive experiences. In the study by Berry and colleagues (2017), for example, the positive bias in the data could be due to the fact that they analysed the hashtag ‘#WhyWeTweetMH’, which actively encouraged positive tweets, rather than studying natural Twitter discussions about mental health. The dominance of positive experiences in these studies could also reflect the positive bias that tends to exist within online communities, whereby people tend to suppress neutral or negative opinions (Askay, 2015). This could also be true for people with dementia since recent offline narratives have tended to focus on positive experiences, particularly ‘living well’ (Birt et al. 2017).

In contrast, Davila and colleagues (2012) suggested that people with depression might use Twitter to ruminate with fellow account holders, which could increase

symptom severity. It is essential then that researchers also examine account holders' negative experiences of using Twitter. This may be particularly relevant for people with dementia, whereby Twitter might perpetuate existing (offline) stigma or further marginalisation of these individuals.

#### **1.6.1.2 Diabetes**

Twitter is a popular space for discussions of diabetes (Beguerisse-Díaz, McLennan, Garduno-Hernandez, Barahona, & Ulijaszek, 2017; Litchman, Lewis, & Gee, 2018; Liu, Mei, Hanauer, Zheng, & Lee, 2016). The hashtag #Dsma (Diabetes Social Media Advocacy), for example, links to a weekly Twitter discussion that provides support for people with type 1 diabetes and allows account holders to communicate with the virtual diabetes community (Liu et al. 2016).

Gabarron, Makhlysheva, and Marco (2015) analysed a sample of tweets containing the hashtags #Type1Diabetes, #T1d, and #Type1. In this dataset, people with diabetes and their families were among the groups of account holders who had the highest frequency of tweets and retweets. The researchers interpreted this as a sign that the tweets of people with diabetes and their families were considered the most interesting by other account holders, but their conclusion was misguided as it equated a retweet with interest. In reality, account holders may choose to retweet something for a variety of reasons, including to demonstrate listening, to express public agreement, and to save for future reading (Boyd, Golder, & Lotan, 2010). Gabarron and colleagues' (2015) findings actually showed that people with type 1 diabetes and their families dominate Twitter discussions of diabetes.

People with diabetes have also used the hashtag '#WeAreNotWaiting' to express their frustrations over the slow development of self-management technology, which

is not available through the medical system (Wicks, 2018). By using this hashtag, people with diabetes have been actively involved in their own medical care by developing bespoke technologies that meet their individual needs. 'Nightscout', for example, is an open-source project that allows real time access to continuous glucose monitoring data on digital devices (Omer, 2016; Riggare, 2018). This suggests that Twitter has enabled people with chronic health conditions to be active contributors to the development of their own medical care. People with dementia could also be using Twitter to facilitate better research and medical care, especially since they have not traditionally been involved in such discussions (Shakespeare, Zeilig, & Mittler, 2019).

The research presented in this section indicates that there is a substantial community of people with diabetes, as well as patient-focused diabetes discussion, on Twitter. Despite this, the findings from these studies lack depth as the vast majority of the research has focused on categorising account holders, identifying their locations, and the frequency of diabetes-related tweets. Although it is important to identify whether people with chronic health conditions are using Twitter, it is also important to move beyond this and engage with their narratives. More in-depth analyses of account holders' tweets could foster better understandings of their experiences, needs, and perspectives, which, in turn, could inform the interventions, policies and practices that affect their lives.

### **1.6.1.3 Cancer**

People with a diagnosis of cancer comprise a substantial community on Twitter (Struck et al. 2018; Sugawara, Narimatsu, Hozawa, Shao, Otani, Fukao, 2012). In a mixed methods analysis, Struck and colleagues (2018) found that Twitter users generated more than 100,000 tweets containing the hashtag '#ProstateCancer' during a 12-month period. Although advocacy and support organisations were the main influencers in discussions about prostate cancer, people living with the diagnosis were also active in these conversations.

The use of Twitter by people with cancer has been examined by Sugawara and colleagues (2012). A content analysis of tweets about treatment by 'power accounts' (i.e. accounts with more than 500 followers) were categorised into psychological encouragement, greetings when visiting the hospital, reports on the outpatient ward, physical condition, and advice for treatment. The sample in this study, however, was limited to power accounts only, resulting in a number of people being excluded from the analysis. The account holders who did not qualify as power accounts may use Twitter differently (e.g. they may use it less frequently or receive less support). In addition, tweets posted by power accounts were only collected across a period of five days. The findings of this study therefore only offer a brief snapshot of how certain people with cancer use Twitter. Future research following account holders over a longer timeframe would facilitate a broader and deeper analysis of all aspects of the illness experience.

More recently, Thomas, Prabhu, Heron, and Beriwal (2018) examined the use of Twitter by people with cancer and healthcare professionals to discuss brachytherapy. They found that people with cancer and healthcare professionals used Twitter to document their experiences and engage in casual conversations

about treatment. The findings of this study suggest that Twitter might be a useful resource for those who are unfamiliar with particular treatments and are looking for information and support. Twitter could serve a similar purpose for people with dementia as this group of people have previously commented on a lack of guidance on treatment and care options (e.g. Millenaar, Bakker, Koopmans, Verhey, Kurz, & de Vugt, 2016).

In another study, Tsuya, Sugawara, Tanaka, and Narimatsu (2014) found that tweets posted by people with cancer were associated with diagnosis, symptoms, and treatment, and this was consistent across almost all types of cancer. Account holders also used medical terminology specific to their type of cancer, suggesting that they used Twitter to share medical information. There was also evidence of cancer-specific content not associated with medical care, such as 'pink ribbon', which was used by people with breast cancer. This indicates that these account holders were also using Twitter to promote fundraising, raise awareness, and self-advocate.

Tsuya and colleagues (2014) did not locate any tweets about treatment or diagnosis for people who had uterine or cervical cancer. Although the authors did not provide an explanation for this, it is possible that the absence of tweets from people with these types of cancer reflect the stigma associated with cervical cancer, due to its association with the sexually transmitted human papillomavirus (Shepherd & Gerend, 2014). This suggests that people with different types of illness may use Twitter in a different way, and face different barriers when they use it. This has direct relevance for research on the use of Twitter by people with dementia as people at different stages of the disease trajectory and people with different types of dementia

might use Twitter for a range of reasons including, but not limited to, information seeking, social support, raising awareness, fundraising, and advocacy.

While these studies have examined the use of Twitter by people with cancer on a large scale, the analyses are descriptive and lack depth, which is likely the result of the computer science methods used to collect and analyse the data. The data mining techniques used by Tsuya and colleagues only focused on the nouns within tweets, thereby failing to account for the greater context of the tweet. In addition, Sugawara and colleagues (2012) and Tsuya and colleagues (2014) only provided broad categories of Twitter usage, failing to conduct a more in-depth analysis. Tsuya and colleagues (2014), for example, reported that people with cancer used Twitter to tweet about diagnosis, but did not specifically analyse what these accounts holders tweeted about their experiences of diagnosis.

Rather than simply relying on an analysis of account holders' tweets, it is also important to engage directly with account holders to gain a greater understanding of their experiences of using Twitter. In a survey of women with breast cancer, Attai, Cowher, Al-Hamadani, Schoger, Staley, and Landercasper (2015) found that Twitter was perceived to be a safe and welcoming forum for support and education, and decreased levels of anxiety among people who had extreme/high anxiety prior to joining Twitter. Whether or not this is also the case for people with dementia, however, is unknown. The knowledge acquired using this survey method could be developed further through the use of qualitative methods, such as in-depth interviews. These methods are required to further examine how and why people with health conditions use Twitter.

In addition to information-seeking, raising awareness, and social support, people with cancer have used Twitter to influence practice and policy. Kate Granger was a



consultant in geriatric medicine who launched the hashtag campaign #HelloMyNameIs after being treated for terminal cancer. The hashtag was designed to remind healthcare staff about the importance of introducing themselves and engaging with patients as people (Granger, 2013). Since the hashtag was launched, #HelloMyNameIs has made over 2 billion impressions on Twitter (Hellomynameis, n.d.). The hashtag also led to a larger campaign of the same name which has seen more than 400,000 health workers across 90 organisations use 'hello my name is' in their practices. This highlights the potential for Twitter to provide people with health conditions a space where they can share their story, gain momentum for their social movement, and make vital changes to the policies that affect their lives, which could also be the case for people with dementia.

Kate Granger used Twitter throughout the cancer trajectory. In an analysis of the tweets posted during the final six months of her life, Taylor and Pagliari (2018) found that a decline in health during the final four weeks of her life was mirrored by a decline in the number of tweets she posted. In contrast to previous phases of the disease trajectory, only one third of Kate's tweets during the dying phases referred to physical and psychological symptoms. Instead, the remainder of the tweets she posted during this time focused on the social and caregiving support she received from her care team, family, friends, and followers.

The findings of Taylor and Pagliari (2018) are interesting because they demonstrate how Twitter can be used to study moments that are traditionally difficult to access. The sample analysed in this study, however, was limited to one high-profile person. A wider and more diverse sample is required to gain a deeper understanding of changes in Twitter use over time. In addition, the researchers only analysed tweets posted during the final six months of Kate Granger's life. An

analysis of tweets posted during different phases of the disease could provide further information about how her use of Twitter changed throughout the disease trajectory.

Like terminal cancer, dementia is progressive and the use of Twitter by people with dementia could change throughout the disease trajectory. While people with dementia may initially use Twitter for campaigning at first, for example, they may use it more for social connection and support as symptoms worsen. Longitudinal research examining the use of Twitter by people with dementia is required to examine this.

#### ***1.6.1.4 Communication disabilities***

Although the consequences of cancer and diabetes can be severe, they rarely affect communication abilities in the way that dementia can. While some people with communication disabilities, like people with other health conditions, have used Twitter for social connection, information sharing, support, and documenting experiences, they have also received additional benefits from using Twitter because of limitations in speech (Brunner, Palmer, Togher, & Hemsley, 2019; Caron & Light, 2016; Hemsley & Murray, 2015; Hemsley & Palmer, 2016). People who use augmentative and alternative communication have reported that the character limits inherent to Twitter are useful for self-expression because they are already accustomed to formulating short messages in communication (Hemsley, Dann, Palmer, Allan, & Balandin, 2015).

More recently, Hemsley, Palmer, Dann, and Balandin (2018) have suggested that Twitter could be used to promote the social inclusion of people with communication disabilities by providing them with a platform through which they can exercise their right to communication. Given that difficulties with language is a common symptom

of dementia (Kilmova & Kuca, 2016), Twitter might also be a useful tool for people with dementia to facilitate communication and social inclusion.

The participants who have taken part in research examining the use of Twitter by people with communication disabilities have tended to have prior experience with communication technologies and short-message communication (e.g. Hemsley et al. 2015). In comparison, people with communication disabilities who do not use augmentative and alternative communication may experience difficulties when learning to use Twitter. This could also be true for some people with dementia, who might not have prior experience using communication technologies or short-text communication, and might have to overcome the initial barrier of learning to use this technology before they can benefit from it.

People with communication disabilities have also used Twitter to communicate their experiences of disability with an audience that extends beyond their direct networks. In a case study of one person with motor neurone disease, Hemsley and Palmer (2016) found that Twitter served as a 'soapbox' for broadcasting thoughts and experiences to the world. Likewise, in a different study, people with communication disabilities reported that Twitter provided them with an audience (Hemsley et al. 2015). These findings suggest that people with communication disabilities have used Twitter to become visible and communicate their experiences of living with disability. Twitter could be equally valuable for people with dementia, whose narratives have only recently been recognised offline.

Although people with communication disabilities have generally reported positive experiences of using Twitter, they have also identified several barriers, including: finding hashtag discussions difficult to keep up with; experiencing embarrassment after tweeting something incorrect; receiving spam; finding it difficult to process all of

the information available; and being the victim of 'trolls' (people who post provocative and offensive messages that create conflict and distress; Buckels, Trapness, & Paulhus, 2014; Brunner et al. 2019; Hemsley et al. 2015). It is likely that people with dementia may face similar difficulties, particularly given the progressive nature of the condition, but there has been no research on this.

Concerns have also been raised about the cognitive demands of using social media for people with acquired communication disabilities. People with traumatic brain injury, for example, have reported feeling cognitively fatigued after using social media (Brunner et al. 2019). This could also be true for people with dementia who might feel fatigued after using Twitter due to deficits in cognition. In addition, researchers have suggested that people with more advanced traumatic brain injury may not be represented on Twitter because of its technical complexity (Brunner, Hemsley, Palmer, Dann, & Togher, 2015). This could also be mirrored in the dementia community, where only those in the earlier stages of dementia might be able to master the technical skills necessary for participation on Twitter.

### **1.7 The use of Twitter by people with dementia**

There has been some research that has examined the content of dementia-related tweets (e.g. Oscar, Fox, Croucher, Wernick, Keune, & Hooker, 2017; Martínez-Pérez, de la Torre-Díez, Bargiela-Flórez, López-Coronado, & Rodrigues, 2015), but only two studies have examined the use of Twitter by people with dementia (Cheng, Liu, & Woo, 2018; Thomas, 2017).

In a netnography (i.e. the conduct of ethnography using the internet; Bowler, 2010), Thomas (2017) found that people with dementia used Twitter to document

their experiences of illness. Thomas (2017) showed that the tweets of people with dementia contain valuable information about their realities and the challenges they face. The sample in Thomas' (2017) study, however, was limited to just two people with dementia.

In a different study, Cheng and colleagues (2018) examined the content and location of tweets containing 'dementia'. These researchers found that people affected by dementia were among the cohort tweeting about dementia, and these account holders tweeted to raise awareness and seek support. Despite claiming that people with dementia are active on Twitter and providing some initial insight into how people with dementia use Twitter, Cheng and colleagues (2018) grouped the tweets of people *with* dementia with those *affected by* dementia. The extent to which people with dementia are using Twitter therefore remains unclear.

Although the findings of Thomas (2017), and Cheng and colleagues (2018), provided an initial basis for understanding the use of Twitter by people with dementia, neither of these studies provide a comprehensive understanding of how people with dementia use Twitter. It remains unclear how and why people with dementia use Twitter, what challenges they face and what benefits it confers, and how their use of Twitter changes across the disease trajectory. More research is therefore required to gain a more comprehensive understanding of the use of Twitter by people with dementia.

## **1.8 Rationale, aims, and objectives**

To summarise this literature review, a movement within dementia research has recognised the personhood, narratives, and citizenship of people with dementia. As well as having their perspectives represented by researchers, people with dementia have communicated their lived experiences and engaged in advocacy to challenge stereotypes, affirm their identities as people who can live with dementia, and encourage social change. Alongside this development, social media has been established and gained in popularity. The social networking site Twitter could be particularly valuable for people with dementia, as other oppressed and marginalised groups have previously used Twitter to communicate their perspectives and create social change. Twitter could be equally valuable for people with dementia, providing a pathway to advocacy and narrative.

People with other chronic health conditions have used Twitter for advocacy, communication, challenging stigma, fundraising, support, and documenting experience, but there has been no comprehensive research examining the use of Twitter by people with dementia. Given the progressive nature of dementia, it is also likely that the use of Twitter by people with dementia will change as symptoms progress, but there is no research on this.

More research on the use of Twitter by people with dementia is required to examine how and why people with dementia use Twitter, and how this changes as the symptoms of dementia progress. This research is important because social media are a ubiquitous part of human life, and it is likely that the number of Twitter account holders with dementia will increase when younger generations, who are more engaged with social media, age.

The overarching aim of this thesis was to explore how and why people with dementia use Twitter. The objectives were to:

- (1) Determine whether people with dementia use Twitter, including estimating how many account holders identify themselves as having a diagnosis of dementia and examining their characteristics through an analysis of their profiles descriptions.
- (2) Explore how people with dementia use Twitter, and through a thematic analysis of their tweets, examine the illness narratives they create and promote online.
- (3) Provide an in-depth examination of how and why people with dementia use Twitter, including how this changes over time, through an analysis of case studies of people with dementia who use Twitter.

## **1.9 Structure of the thesis**

This thesis comprises eight chapters: this introduction, a methods chapter, four empirical papers, a reflexive statement, and a general discussion. Chapters 3-6 are presented as versions of journal articles that have been published or have been prepared for submission to journals.

Chapter 2 presents the epistemological stance that informed the methodological choices of this thesis. It includes details of the design, recruitment and study procedures, and analytical methods used in this thesis. Information about the patient and public involvement group who advised on this research and ethical considerations are also presented in this chapter.

Chapter 3 is the first empirical chapter of this thesis. It provides an estimation of the number of Twitter account holders who identified themselves as having dementia and examines the characteristics of these account holders through a content analysis of their Twitter profiles. Chapter 4 explores how 12 account holders with dementia used Twitter and, through a thematic analysis of their tweets, examines the illness narratives they created and promoted online.

Chapter 5 and Chapter 6 present the findings of an analysis of case studies of people with dementia who used Twitter. Chapter 5 reports the findings of a thematic analysis of these case studies to examine, in their own words, how and why people with dementia used Twitter. Chapter 6 identifies how the use of Twitter by people with dementia changed over time through a longitudinal analysis of these case studies.

Chapter 7 is a reflexive statement. Chapter 7 presents critical reflections on the impact of my disciplinary background, lived experience, and personal characteristics upon the research process.

Finally, Chapter 8 is the overarching discussion of the thesis. In this chapter, the rationale, aims, objectives, and results of the research are summarised. The findings of this research are then discussed in relation to the wider literature on dementia advocacy and identity, illness narratives, and social media. Following this, the methodological and theoretical contributions are discussed. The limitations of the thesis are then outlined, before considering the practical applications and future research directions of this research.



## **Chapter 2**

### **Methods**

## 2.1 Summary

This chapter presents the epistemological stance that informed the methodological choices of this thesis. The purpose of this chapter is to provide additional information about the methods used in this thesis that could not be included in the empirical chapters because they have been written concisely for publication. Information about the patient and public involvement group who advised on this research and ethical considerations are also outlined in this chapter.

## 2.2 Epistemology: Generic, Pragmatic Qualitative Research

A generic, pragmatic qualitative perspective was adopted to examine the use of Twitter by people with dementia. In pragmatic qualitative research, the research question drives the methodology (Morgan, 2007). Generic qualitative research refers to qualitative research that does not align with a specific approach, such as ethnography, grounded theory, or phenomenology (Kennedy, 2016). Using a generic qualitative perspective, the researcher seeks to discover and understand a process, phenomenon, or the perspectives and experiences of a group of people (Percy, Kostere, & Kostere, 2015; Caelli, Ray, & Mill, 2003). A generic, pragmatic qualitative approach was taken because the focus of the research was the *experiences* and *perspectives* of people with dementia.

Merriam (2009) argued that qualitative inquiry often begins as generic qualitative research, and a chosen methodology that is informed by a theoretical framework adds an additional dimension, through which the researcher can understand experience and its construction. A generic, pragmatic approach can be particularly useful for exploratory work in under-researched, under-theorised areas (Pistrang &

Barker, 2012). The use of Twitter by people with dementia is a relatively new phenomenon; consequently, theoretical understandings are limited. It was therefore appropriate to adopt a generic, pragmatic qualitative perspective.

## **2.3 Overview of the Thesis**

A generic, pragmatic qualitative perspective guided the design of three separate studies, which examined how and why people with dementia use Twitter. These three studies were conducted sequentially with each study building on the methods and knowledge gained from the previous study. Study One identified people with dementia on Twitter and, through a content analysis of their profiles descriptions, examined the characteristics of these account holders. Study Two was a thematic analysis of the tweets posted by account holders who identified themselves as having dementia. Study Three comprised thematic and longitudinal analyses of case studies of people with dementia who used Twitter. Additional information about the methods used in these studies is detailed below.

### **2.3.1 Study One (Chapter 3)**

The aims of Study One were to: (1) determine whether people with dementia use Twitter; (2) estimate the number of Twitter account holders who publicly identify themselves as having a diagnosis of dementia; and (3) examine the demographic characteristics of these account holders.

### ***2.3.1.1 Identifying Twitter account holders with a diagnosis of dementia***

A scoping exercise was initially conducted to identify account holders who reported having a diagnosis of dementia in their profile descriptions. The purpose of this scoping exercise was to determine whether the account holders identified in these initial searches could later be located within the data. The search terms “person with dementia”, “living with dementia”, “dementia advocate”, and “dementia activist” were entered into the search bar of Twitter to identify account holders. The tweets of dementia advocacy groups and projects (e.g. @DementiaVoices, @DementiaTweets) were also examined to identify account holders who were mentioned in these tweets and identified themselves as having dementia.

Entering search terms into the search bar of Twitter is not, however, a systematic method of identifying account holders nor does it provide a comprehensive list of Twitter users who identify themselves as having dementia. While it is not currently possible to search for Twitter account holders by their profile descriptions, it is possible to use data extraction software to sample tweets and the profiles descriptions of the account holders who posted them.

The data extraction software, Tweetcatcher was used to identify tweets containing the search terms “dementia” or “Alzheimer” (Brooker, Barnett, & Cribbin, 2016). Tweetcatcher uses the Search Application Programming Interface (API) of Twitter to identify tweets that have already been posted. Researchers have successfully used Tweetcatcher in the past to collect tweets (e.g. Barnett et al. 2018). Ahmed and Bath (2015) have estimated that the freely available Search API provides access to 74% of tweets that have been posted, whereas the costly Firehouse API allows access to 100% of tweets. Free software was used in this research because the cost of

accessing the Firehouse API was beyond the scope of a PhD research project, costing up to \$1,899 per month (Twitter, n.d.).

Before conducting this study, the number of tweets collected by Tweetcatcher and different data extraction software (i.e. Ncapture) were compared. Tweetcatcher identified a greater number tweets and was used in Study One with the aim of maximising the number of tweets collected, which, in turn, increased the likelihood of identifying a greater number of account holders with a self-reported diagnosis of dementia.

In a pilot test, Tweetcatcher was used to identify tweets containing the search terms 'dementia' and 'Alzheimer' that were posted during a 24-hour time period. Many of the account holders identified in the initial scoping exercise were not located within the data, so the search timeframe was increased to one month with the aim of identifying a larger sample.

On 12<sup>th</sup> June 2017 16:42 (GMT), Tweetcatcher was used to identify tweets posted in the previous 24 hours that contained that the search terms 'dementia' or 'Alzheimer'. This search was repeated every 24 hours for 30 consecutive days. Tweetcatcher collected the contents of each tweet and the following information from the profiles of the account holders who posted each tweet: username; real name; location; profile description; number of tweets; number of followers; number following.

Tweetcatcher identified a total of 416,826 tweets, including 226,602 retweets, that contained the terms 'dementia' or 'Alzheimer' during the 30-day period. Once the tweets had been collected, the sample was imported into Microsoft Excel for analysis. The sample was screened for multiple tweets posted by the same account holder, reducing the final sample to 217,623 tweets, including 132, 628 retweets.

The profile descriptions of account holders were then systematically searched for evidence of a dementia diagnosis. The systematic search strategy was developed from the profile descriptions of the sample identified in the initial scoping exercise. The search strategy included, but was not limited to, the following statements: statements of having a diagnosis (e.g. 'I have', 'person with'); different types of dementia (e.g. Alzheimer's); groups led by people diagnosed with dementia (e.g. Dementia Action Alliance). For a full list of search terms, see Appendix C. Using these search terms, 30 account holders with a self-reported diagnosis of dementia were identified.

#### **2.3.1.2 Content analysis**

A content analysis was conducted on the profile descriptions of account holders who identified themselves as having dementia. Content analysis is "a technique for examining information and content, in written or symbolic materials" (Neuman 1997, p. 31). In a content analysis, large quantities of text are organised into fewer content categories. These categories refer to patterns or themes that are directly expressed in the text or derived through the analysis (Marks & Yardley, 2004).

It was appropriate to conduct a content analysis because the units of analysis were micro-texts (Wilkinson, 2000), such as individual words or phrases that account holders used to describe their characteristics, diagnostic information, the activities they were involved in, and the roles they occupied. Codes for content included: gender; current age; age at diagnosis; type of dementia; description of dementia; advocacy activities; affiliations with dementia organisations or groups; and social identities beyond the dementia diagnosis. 'Description of dementia' referred to how the account holders described their condition, such as 'living with dementia' or being

a 'dementia patient'. 'Social identities beyond the dementia diagnosis' referred to other social roles account holders occupied beyond their identities as people with dementia, such as a father, football fan, and an animal lover. This data was analysed descriptively to examine the frequencies of each content category.

### **2.3.2 Study Two (Chapter 4)**

Study Two was a thematic analysis of the tweets posted by account holders who identified themselves as having dementia. The aims of this research were to: (1) identify how people with dementia use Twitter; and (2) examine the extent to which people with dementia use Twitter to create and promote identities related to their illness.

#### **2.3.2.1 Sampling**

Participants were purposively sampled from the population identified in Study One. Maximum Variation Sampling was used to recruit account holders. The purpose of using this sampling approach was to achieve representativeness and expand the range of differences within the sample, so that diverse variations of Twitter usage could be examined, and the patterns that cut across these variations could be identified (Patton, 2002; Palinkas et al. 2015).

Using the information reported by the account holders in Study One, a Maximum Variation Sampling framework was developed using type of dementia (Alzheimer's disease, vascular, Lewy body, frontotemporal, mixed, rare, not specified), location (United Kingdom, Australia, United States of America), and sex (man, woman) as dimensions to accommodate as much variation as possible. Sampling was guided by this framework, where one man and one woman with each type of dementia were

sampled from each location. When there was more than one person of the same sex, with the same diagnosis, from the same location, random sampling was used to select a single account holder. Not all cells in the sampling framework were filled.

Thirteen account holders were included in the initial sample. One account holder was excluded from the sample because she had advised on this research project. Instead, a different account holder with the same demographic variables was included in the sample. A second account holder was excluded from the sample because of a change in personal circumstances. Another person with the same demographic variables replaced this account holder. It also became clear during the analysis that one account was jointly owned by a person with dementia and her carer, and was therefore excluded from the sample. A total of 12 account holders were included in the final sample.

#### **2.3.2.2 Procedure**

The sample were tweeted informing them that their tweets were being used for research purposes. These account holders were asked to direct message the researcher if they wanted to ask any questions or opt out of the research. The ethical frameworks underpinning this research are discussed later in this chapter.

Following this, Tweetcatcher (Brooker et al. 2016) was used to identify tweets and retweets posted by the 12 account holders during the preceding six months. Tweets were collected on 2nd November 2017, before Twitter increased the character limit of tweets to 280 characters. A total of 11,527 tweets (including 6,788 retweets) was collected from the Twitter profiles of the sample. Retweets without comments were excluded from the analysis to focus on more substantive tweets. Conversational



tweets aimed at specific account holders (i.e. tweets beginning with '@') were not included in this analysis because the complete conversation was unavailable. A total of 2,774 tweets were included in the analysis.

Some of the tweets identified by Tweetcatcher were incomplete. To obtain the full tweet, the hyperlink identified by Tweetcatcher was followed and the original tweet was manually imported into the dataset. Emojis were retained in tweets manually imported into the dataset. As well as identifying tweets, Tweetcatcher also collected hyperlinks to images posted by account holders; however, only the tweet itself was analysed in this study (i.e. not the image).

### ***2.3.2.3 Thematic analysis***

Tweets were analysed using thematic analysis. Thematic analysis is “a method for identifying, analysing, and reporting patterns within data” (Braun & Clarke, 2006, p.79). Braun and Clarke’s (2006; 2013) approach to thematic analysis was used to analyse tweets, which has recently been coined reflexive thematic analysis (Braun, Clarke, Hayfield, & Terry, 2019; Braun & Clarke, 2019). This approach was taken because it is theoretically flexible and, consequently, aligns with generic, pragmatic qualitative epistemology. Reflexive thematic analysis can also be used to analyse a variety of media (Braun & Clarke, 2006, 2014). This was advantageous because thematic analysis was not traditionally designed to analyse short-text data, such as tweets.

Braun and Clarke’s (2006) approach to coding is flexible, organic, and evolves throughout the coding process. This was important, because theoretical understandings about the use of Twitter by people with dementia are limited, and as

such it would not be appropriate to conceptualise codes and themes early in the analytic process (either before the analysis or after data familiarisation). Braun and Clarke's approach provided the flexibility required to fully explore the data and answer the research questions.

The thematic analysis followed six steps: data familiarisation through reading a sample of tweets; generating initial codes and coding the entire dataset in NVivo 11; collating codes and relevant tweets together; examining codes to identify themes across the data; reviewing and refining the themes; and defining and naming the themes (Braun & Clarke, 2006). Additional information about how this analysis was conducted is reported in Chapter 4.

Braun and Clarke (2019) argued that reflexivity is important in qualitative research as the researcher brings his or her own theoretical assumptions and life experiences to the research, which guides the analysis. It is important that researchers are both aware of and transparent about these assumptions throughout the analysis and reporting of the research. In line with this approach, any theoretical assumptions or life experiences that may have influenced the analysis and reporting of the data are discussed later in this thesis (see Chapter 7).

By acknowledging the role of the researcher in the analysis, Braun and Clarke (2019) rejected the idea that themes emerge from the data. Instead, themes are actively generated through the researcher's active involvement with the data (Braun & Clarke, 2019). A team-based approach to analysis was adopted when conducting the qualitative research presented in this thesis, whereby data were discussed with a supervisory team and a group of qualitative researchers at the University of Exeter. The aim of this approach was to promote rigour, elucidate theoretical assumptions that may have affected the analysis, and achieve a more nuanced reading of the

data. The value of this approach to qualitative analysis is discussed later in the thesis (see Chapter 7).

### **2.3.3 Study Three (Chapter 5 and Chapter 6)**

Study Three was an analysis of case studies of ten people with dementia who use Twitter. This study comprised thematic and longitudinal analyses over a time-period of one year. The aims of this study were to: (1) examine, in their own words, how and why people with dementia use Twitter; and (2) examine how the use of Twitter by people with dementia changes over time.

#### **2.3.3.1 Case studies**

A case study is an in-depth methodological approach that facilitates the exploration of a given phenomenon using multiple sources of data (Yin, 2009). A case refers to a unit of analysis, which Miles and Huberman (1994, p25) have defined as “a phenomenon of some sort occurring in a bounded context”. A case can refer to an individual, group, organisation, program, or process (Baxter & Jack, 2008). For the purposes of Study Three, a single case was a person with dementia.

Yin (2003) argued that case study designs are appropriate when: (1) the focus of the study is to answer “how” and “why” questions; (2) the behaviour of participants cannot be manipulated; (3) the focus is to identify contextual conditions that are relevant to the phenomenon being studied; or (4) the boundaries between the phenomenon and context are unclear. The case study method was, therefore, appropriate for this research because the research questions focused on *how* and

why people with dementia use Twitter. The case study method was also suitable because participants' symptoms of dementia could not be manipulated, and a focus of the research was to examine how the contextual conditions (e.g. the direct effects of dementia on cognition and functional ability) affected participants' use of Twitter.

### **2.3.3.2 Interviews and measures**

Interviews, operationalised measures of cognition and functional ability, and tweet frequency data were included in the study design. Although a qualitative approach was taken, operationalised measures were included in the study design so that the direct effects of dementia on cognition and functional ability could be examined. Participants' scores across these measures were then used to make interpretations when conducting the qualitative analysis. It was also important to include these measures so that cases of cognitive and functional decline could be identified. An assumption was therefore made that participants' symptoms of dementia would progress during the study timeframe.

#### **2.3.3.2.1 Interviews**

In-depth, semi-structured interviews were conducted with participants on entry to the study, and at six- and 12-month follow-up. Qualitative interviewing allows a researcher to examine the everyday lives of participants and the meaning they attach to their experiences (Kvale & Brinkmann, 2009). Consequently, interviews were included in the study design to facilitate an in-depth examination of participants' lived experiences.

Interviews were split into two parts. In the first part of the interviews, participants were asked about their experiences of using Twitter, which was guided by an

interview schedule. Consistent with the semi-structured interview method, interview guides were developed for each time point (see Appendix J-L). The interview guide for the initial interviews focused on reasons for joining Twitter, reasons for using Twitter, self-presentation, interactions, and barriers. The interview schedules for follow-up interviews focused on changes in symptoms of dementia and Twitter usage. All interview schedules were reviewed by the supervisory team and a person with dementia who advised on the project. This was to ensure that relevant topics were covered, questions were asked in the right order, and the language was accessible. After receiving feedback, amendments were made to the guide by adding, removing, rephrasing, or changing the order of questions where appropriate.

The second section of the interviews followed an adapted version of the scroll back method (Robards & Lincoln, 2017). In Robards and Lincoln's (2017) research, participants were asked to scroll through their Facebook posts and discuss them with the researchers as part of semi-structured interviews. Robards and Lincoln (2017) argued that the scroll back method can be used to better understand peoples' use of social networking sites. The scroll back method allows researchers to view the content of participants' social media profiles and encourages them to engage with the research process as co-analysts of their posts. The scroll back method was included in the design of Study Three to elucidate additional information about participants' use of Twitter, and to stimulate memories as the scroll back method relies on recognition rather than free recall. It was therefore assumed that the scroll back method would facilitate focused discussions with participants.

In Study Three, the scroll back method was adapted by using tweets rather than Facebook posts. This method was adapted further by using printed examples of participants' tweets, rather than asking them to scroll through their Twitter profiles on

a laptop or tablet device (see Appendix M for an example). Participants were presented with a random sample of 10 of their tweets and were asked to explain why they posted each tweet, what they hoped to achieve by posting the tweet, how they felt at the time they sent the tweet, and what type of reaction the tweet provoked.

#### *2.3.3.2.2 Measures of cognition and functional ability*

The Mini Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) was used as a measure of cognition. The MMSE comprises 30 questions that assess orientation, language (naming, repetition, reading, and writing), registration, memory, calculation, and visual-construction. Scores on the MMSE range from 0-30 and scores less than 25 are typically considered to indicate cognitive impairment (Folstein, Folstein, McHugh, & Fanjiang, 2001).

The MMSE was used in this study because it is the most widely used measure of cognition (Sheehan, 2012) and is commonly used as a core outcome measure in trials (Webster et al. 2017). The MMSE was also included in the study design because it is quick to administer, lasting approximately 10-15 minutes. It was important that the measure of cognition was quick to administer because the main focus of each meeting was the interview.

Lawton and Brody's Independent Activities of Daily Living (IADL; 1969) scale was used as a measure of functional ability. This measure was chosen because it is quick to administer and widely used as a measure of functional ability (Sikkes, de Lange-de Klerk, Pijenburg, Scheltens, & Uitdehaag, 2008). The self-rated version of the IADL scale was used, which has also commonly been used in research measuring functional ability (Lawton & Brody, 1988; Yang et al. 2014).

Self-report measures have been frequently used in health research to measure participants' subjective feelings and behaviour without the need for extensive observation (del Boca & Noll, 2000; Schwarz, 1999). In dementia research, however, self-report measures have been used infrequently (Martyr & Clare, 2012), which could reflect an assumption that people with dementia lack awareness (Clare, Marková, Roth, & Morris, 2011). Despite this, researchers have recently demonstrated that people with dementia are able to rate their functional ability with reasonable accuracy when compared to informants, who tend to underestimate the functional ability of people with dementia (Martyr, Nelis, & Clare, 2014; Martyr & Clare, 2018). The self-rated version of the IADL scale was therefore considered an appropriate measure of functional ability.

#### *2.3.3.2.3 Tweet frequency*

Monthly tweet frequency was included in the study design to identify increases or decreases in the monthly number of tweets sent by participants. Twitter Analytics was used to access tweet frequency data. Twitter Analytics is a free service provided by Twitter that allows users to examine their social media analytics. Frequency of retweets were not included in this measure because Twitter Analytics does not collect this data.

#### **2.3.3.3 Recruitment**

Participants were sampled from the population of Twitter users identified in Study One. The target sample size was 10-15 people, which is consistent with recommendations for interview studies that aim to identify patterns across data and describe a shared behaviour among a relatively homogenous group (Guest, Bunce, & Johnson, 2006). For practical reasons, the sample was limited to account holders located in the UK. Fourteen account holders were tweeted informing them of the research. Five of these account holders consented to take part in the study.

To increase the size of the sample, Twitter was searched for UK account holders who identified themselves as having dementia and were not located in Study One. Existing participants and advisors on the study were also asked if they knew of anyone who might be interested in taking part in the research. A further six people with dementia consented to take part in the study, resulting in a final sample of 11 participants.

#### **2.3.3.4 Procedure**

Participants completed the self-rated version of the IADL scale before interviews. Following this, participants were met at their homes or a place of their choosing. The MMSE was then administered to participants. All participants completed the serial sevens calculations task at each timepoint and, consequently, no participants completed the task where they are asked to spell “world” forwards and backwards. After completing the MMSE, interviews were conducted with participants, including the scroll back method. Interviews were recorded using a digital device and ranged in length from 35–80 minutes. This process was repeated six- and 12-months after



the initial interview. After interviews at six- and 12-month follow-up, participants' Twitter Analytics data were accessed to record monthly tweet frequency.

### **2.3.3.5 Analyses**

#### *2.3.3.5.1 Thematic analysis*

Interview data were first analysed qualitatively using Braun and Clarke's (2006; 2013) approach to thematic analysis. As discussed earlier in this chapter, thematic analysis was used because it aligns with a generic, pragmatic approach and has been commonly used in qualitative research that aims to identify patterns of meaning (Braun & Clarke, 2006, 2013). Responses at the initial interviews (including the scroll back method) and answers to clarifying questions at six- and 12- month follow-up were analysed together. Additional information about how this analysis was conducted is reported in Chapter 5.

Originally, the data collected using the scroll back method was supposed to be analysed separately; however, participants' responses often did not answer the research question or were not substantial enough to warrant a separate analysis. Some reflections on using the scroll back method with people with dementia are outlined in Chapter 8.

#### *2.3.3.5.2 Longitudinal analysis*

Scores on the MMSE and IADL scale, and frequency of tweets were tabulated and analysed descriptively to examine changes across these measures. The original plan of analysis involved conducting a trajectory analysis of the interview data by mapping each participant's use of Twitter across the disease trajectory (Grossoehme & Lipstein, 2016). An assumption was therefore made that the MMSE and IADL

scores of participants would decline during the 12-month time-period. Following data collection, however, it became evident that there were no instances of substantial decline across participants.

Instead, a recurrent cross-sectional analysis was conducted to analyse interview data. A recurrent cross-sectional analysis explores themes and changes over time across participants, and is appropriate when the aim is to compare timepoints (Grossoehme & Lipstein, 2016). A framework approach was used to facilitate the longitudinal analysis of qualitative data, which comprised a series of time-ordered matrices (Miles & Huberman, 1994). This approach was used because it provided a clear structure for organising the qualitative data, which made processes and patterns of change identifiable. Additional information about how this analysis was conducted is reported in Chapter 6.

## **2.4 Patient and Public Involvement**

Patient and public involvement (PPI) involves carrying out research *with* people, rather than *on* them (INVOLVE, 2012a). INVOLVE stated “people who are affected by research have a right to have a say in what and how publicly funded research is undertaken” (INVOLVE, 2012b, p8). In addition, including patients and the public as advisors on research projects can provide a unique perspective from those with lived experience (Simpson & House, 2002). PPI involves a range of activities, including consultation about ideas for research, contributing towards ethical debates and the design of studies, data collection and interpretation, dissemination of findings, and the development of research-related policy (Gove et al. 2018).

Three people with dementia who used Twitter advised on the research presented in this thesis. Contact with the PPI group took place via email and the group assisted with the following tasks:

- Identifying an appropriate length of time for an interview and the number of breaks required.
- Identifying search terms that people with dementia reported in their profiles descriptions.
- Reviewing interview schedules to ensure language was appropriate, questions were relevant, and asked in a suitable order.
- Reviewing information sheets and consent forms to ensure they were accessible.
- Participating in pilot interviews.
- Reviewing themes generated in Study Two and Study Three.

## **2.5 Ethical Considerations**

### **2.5.1 Social media research ethics**

While developments in technology have created novel opportunities for research, they also present ethical challenges. Ethical guidelines for social media research focus on issues of privacy, anonymity, and consent (Markham & Buchanan, 2012; British Psychological Society, 2017). The British Psychological Society code of Ethics and Conduct (2014) states that unless consent has been sought, observation of public behaviour must take place in spaces where individuals would expect to be observed by strangers. This has led to debates about whether the online spaces of social media are public or private; however, there is a consensus among researchers

that public social media profiles reside within the public eye and can be used for research purposes (Markham & Buchanan, 2012; British Psychological Society, 2017; Moreno, Giniu, Moreno, & Diekema, 2013). In this research, Twitter was considered a public space. This was because the purpose of using Twitter is to gain retweets and followers, and to share information with a wider audience. In addition, the Twitter data reported in this thesis were restricted to public accounts, meaning no private accounts were included in the research.

In traditional forms of qualitative research, data are anonymised to protect the identity of participants. In research that uses tweets as data, however, it is not possible to guarantee the anonymity of account holders. This is because a Google search of quoted tweets could lead directly to the accounts from which the tweets were posted. Despite this, there is general agreement among social media researchers (and the ethics committees that approved their research) that tweets are publicly available data and account holders cannot expect anonymity or confidentiality (Markham & Buchanan, 2012; British Psychological Society, 2017).

While it is often assumed that social media account holders want to protect their anonymity, certain researchers have suggested that some account holders may expect to have their tweets quoted and may tweet publicly in order to advocate for a particular position (McKee, 2013). Bassett and O’Riordan (2002) referred to this as a ‘political imperative for visibility’ in which there is a need for representation of groups of people who have been underrepresented in other forms of media. This is directly relevant for research conducted with people with dementia who’s perspectives have traditionally been underrepresented in research, policymaking, and public life.

Issues of privacy and anonymity relate to whether researchers are ethically bound to seek consent from social media account holders. In many cases, Twitter

researchers will access and analyse data without seeking consent or informing the account holder of the research. In this research, however, each account holder was tweeted to give them the opportunity to opt out of the analysis. This approach has been used successfully in previous social media research (e.g. Anderson, Hundt, Dean, Keim-Malpass, & Lopez, 2017) and is consistent with account holders' attitudes towards using social media data for research purposes (Fiesler & Proferes, 2018).

### **2.5.2 Ethical considerations for research conducted with people with dementia**

One universal ethical consideration in research conducted with people with dementia concerns their capacity to consent to take part in research. The Mental Capacity Act (Department of Health, 2005), however, states that people should be assumed to have capacity unless they demonstrate otherwise. Capacity is demonstrated through a person's ability to understand and retain information about the research, to evaluate that information in order to reach a decision, and to state a decision clearly. In line with the Mental Capacity Act, the account holders in Studies One through Three were originally assumed to have capacity. In addition, participants were required to be users of Twitter in order to take part in this study, meaning it was highly likely that they had capacity.

When Study Three participants were met at the initial interviews, a checklist created by the Centre for Research in Ageing and Cognitive Health (REACH) was used to ensure that the criteria for capacity were met (see Appendix H). If there was any doubt about capacity, consent was not taken. In this research, however, all participants demonstrated that they had capacity.

## **2.6 Summary**

This chapter has provided a summary of the methods used in this thesis. This chapter has also provided additional information about: the epistemological stance that informed the methodological choices of the thesis; how people with dementia were originally identified on Twitter; the patient and public involvement group who advised on this research project; and the ethical considerations of this research. The next four chapters are the empirical chapters of the thesis that examine how and why people with dementia use Twitter.

## **Chapter 3**

### **Identifying People with Dementia on Twitter**

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Talbot, C., O'Dwyer, S. T., Clare, L., Heaton, J., & Anderson, J. (2018). Identifying People with Dementia on Twitter. *Dementia*, 0(0), 1-10.

### **3.1 Rationale and Research Aims**

Recent research has shown that people with dementia have used Twitter for support and documenting experiences (Thomas, 2017; Cheng et al. 2018). However, the extent to which people with dementia are represented on Twitter is unknown, and researchers have yet to examine the demographic characteristics of these account holders. This information is crucial in order to identify whose voices are represented on Twitter and, importantly, whose voices are not. It is unclear whether certain groups of people with dementia, such as women and people with rare types of dementia, are underrepresented on Twitter as is often the case in offline spaces (e.g. Bartlett, Gjernes, Lotherington, & Obstefolder, 2018), or whether Twitter is providing a more equitable spaces for the voices of all people with dementia to be heard. This lead us to the aims of this brief report, which were to (1) determine whether people with dementia are using Twitter; (2) estimate the number of Twitter account holders who publicly identify themselves as having a diagnosis of dementia; and (3) examine the demographic characteristics of these account holders. The study was approved by the Human Research Ethics Committee of the University of Exeter Medical School.

### **3.2 Method**

#### **3.2.1 Data collection**

On 12<sup>th</sup> June 2017 16:42 (GMT), the first author (CT) used the data extraction software programme Tweetcatcher, which uses Twitter's Search Application Programming Interface (API) to identify past tweets using predefined keywords (Brooker et al. 2016), to identify tweets posted in the previous 24 hours that



contained the search terms 'dementia' or 'Alzheimer'. It is not currently possible to search for Twitter account holders by their profile descriptions, only by their tweets, so this is the only viable method of collecting Twitter data (Kumar, Morstatter, & Liu, 2014). Once the tweets are located, it is then possible to examine the profiles of the account holders who posted them.

The search was repeated every 24 hours for 30 consecutive days. For each tweet, the contents of the tweet and the date and time of posting were collected. The following information was collected from the Twitter profile of the account holder who posted the tweet: username, real name, location, profile description, number of tweets, number of followers, and number being followed.

### **3.2.2 Sample**

Tweetcatcher identified 416,826 tweets containing the terms 'dementia' or 'Alzheimer' during the 30-day period. This included 226,602 retweets. CT screened the sample for multiple tweets by the same account holder, reducing the final sample to 217,623 tweets (including 132,628 retweets).

Tweets and account holder data were imported into Microsoft Excel for analysis. The profile descriptions of the account holders were searched by CT for any evidence of a dementia diagnosis. A systematic search strategy was developed by CT and a patient and public involvement group to identify account holders with a self-reported diagnosis of dementia. All the co-authors commented on the search strategy and amendments were made where appropriate. The search strategy included the following: statements of having a diagnosis (e.g. 'I have dementia', 'diagnosis'); different types of dementia (e.g. 'frontotemporal'); and campaigns or groups led by people diagnosed with dementia (e.g. "Scottish Dementia Working

Group”, “SDWG”). Account holders were excluded from the sample if they belonged to organisations, were researchers or carers, or were individuals who did not identify as having dementia. For practical reasons, only accounts written in English were included in the sample.

### **3.2.3 Data Analysis**

A content analysis was conducted by CT to identify the characteristics of the sample. In a content analysis, large quantities of text are organised into fewer content categories. These categories refer to patterns or themes that are directly expressed in the text or derived through the analysis (Marks & Yardley, 2004). Codes for content were gender, current age, age at diagnosis, type of dementia, description of dementia, advocacy activities, affiliations with dementia groups, and social identities beyond the dementia diagnosis. ‘Description of dementia’ referred to how the account holders described their condition, such as ‘living with dementia’ or being a ‘dementia patient’. ‘Social identities beyond the dementia diagnosis’ referred to other social roles account holders occupied beyond their identities as people with dementia. Descriptive analyses were conducted to identify the relative frequency of each content category.

### 3.3 Results

Of the 217,624 account holders tweeting about dementia, 30 publicly identified themselves as having a diagnosis of dementia. The average age was 59 years (range: 37–88), they had been on Twitter for an average of five years, and the majority were men. The full list of demographic characteristics is reported in Table 3.1.

Table 3.1. *Participant demographics.*

Characteristic	Mean (SD)	Range	N
Time since first joined Twitter (years)	4.57 (2.61)	0–9	
Number of tweets	13,900 (28600)	82–130,932	
Number of followers	1930 (2330)	44–8337	
Number following	1406 (1715)	50–7462	
Age (years)	58.6 (15.8)	37–88	7
Age at diagnosis	51.3 (1.77)	50–52.5	2
Gender			
Male			17
Female			12
Unknown			1
Location			
United Kingdom and Ireland			15
North America			12
Australia			1
Unknown			2

The majority of account holders ( $n=18$ ) specified the type of dementia with which they had been diagnosed, with Alzheimer's disease being the most common (see Table 3.2).

Table 3.2. *Twitter account holders' self-reported type of dementia.*

Type of dementia	N
Not specified	12
Alzheimer's disease	8
Lewy body dementia	3
Posterior cortical atrophy	2
Frontotemporal dementia	2
Mixed dementia	1
Atypical Alzheimer's disease	1
Vascular dementia	1

Eight Twitter account holders described themselves as having young-onset dementia (i.e. onset of symptoms before the age of 65). Two account holders gave their ages at the time of diagnosis, which were 50 and 52.5, respectively.

Although descriptions of dementia varied considerably, the majority of account holders ( $n=16$ ) described themselves as 'living with' or 'living well with' dementia. Other descriptions included 'having a diagnosis' of dementia ( $n=4$ ), 'having' dementia ( $n=3$ ), 'person with' dementia ( $n=1$ ), and being a 'dementia survivor' ( $n=1$ ). One female account holder described herself as a 'patient'.

Seven account holders identified themselves as dementia activists/advocates, and 10 were affiliated with working groups such as the Scottish Dementia Working

Group, the Three Nations Dementia Working Group, or the European Dementia Working Group.

Fourteen account holders reported social identities beyond their dementia diagnosis. These included father, football fan, and animal lover.

### **3.4 Discussion**

To our knowledge, this is the first study to examine the use of Twitter by people with dementia, and the results clearly show that people with dementia are active on Twitter. Eight account holders reported having young-onset dementia, the average age of account holders was 59 years, the average age at diagnosis was 51 years, and the majority were located in North America or the United Kingdom. Although Alzheimer's disease was most commonly reported, a range of diagnoses were evident, including rare forms of dementia such as posterior cortical atrophy. The majority of account holders reported 'living with' dementia and considered themselves a dementia advocate or were affiliated with a dementia working group. Only 40 percent of the account holders identified in this study were female.

Although the population identified in this study is relatively small when compared with the organisations, health professionals, and general public who contribute to dementia-related content on Twitter (Robillard, Johnson, Hennessey, Beattie, & Illes, 2013; Oscar et al. 2017), it is likely to increase as digital natives and immigrants age (Prensky, 2001). Social media platforms such as Twitter are expected to become an integral aspect of living with dementia as 'tech-savvy' generations approach later life, and this is already evident in the relatively young age of the sample in this study. Twitter and other social media platforms may be changing the lived experience of

dementia by facilitating greater social connection, engagement, and self-expression than has been possible for pre-Web 2.0 cohorts.

Previous research on the use of social media by people with dementia has either not specified the type of dementia (Rodriquez et al. 2013) or has focused on people diagnosed before the age of 65 (Craig & Strivens, 2016). The current study provides evidence that people with a range of different dementia diagnoses are active on Twitter. Although the majority of account holders reported having Alzheimer's disease or did not specify their diagnosis, other types of dementia (including rare forms of dementia) were evident. This could be because people under the age of 65 are more likely to be diagnosed with a rare type of dementia (Dickerson et al. 2017), such as posterior cortical atrophy, and are also more likely to use Twitter (Greenwood, Perrin, & Duggan, 2016).

The range of dementia types identified in this study echoes the findings of Sugawara et al. (2012) which showed that people with a range of cancer types, such as breast, stomach, prostate, and liver cancer are active on Twitter. People with different types of dementia could use Twitter for different reasons and gain different benefits from it. People with rare forms of dementia, for example, might use Twitter to share their experiences with a wider audience and to raise awareness of non-Alzheimer's conditions, while those with more common forms of dementia might use it for social support or information seeking. Although it is beyond the scope of this study, research that examines the tweets of people with different types of dementia could be used to identify differences in the Twitter behaviour of those with rare and common conditions and those with young and later onset.

The majority of account holders in this study were men and were relatively young, yet the prevalence of dementia in the general population is greater for women and

people over the age of 65 (Ludwin & Parker, 2015; Prince et al. 2014). This finding contrasts with the findings of prior research regarding the use of Twitter by people with cancer, in which men and women were equally represented on the platform (Sugawara et al. 2012). It is possible that, despite its potential for giving voice to the marginalised and oppressed, Twitter might not be providing a platform for all people with dementia. Instead, the dominance of younger and male dementia voices on Twitter might be perpetuating the marginalisation and stigma experienced offline, especially by older women with dementia. This could also be reflective of the demographics of Twitter users, where those over the age of 65 make up the smallest proportion of account holders (Greenwood et al. 2016).

In this study, the diagnosis of dementia was self-reported in Twitter 'bios', so it was not possible to identify the stage of dementia or the type of impairments account holders are living with. Although it is likely that it is mainly people with less severe dementia who are using Twitter, this can only be confirmed through research that moves beyond data collected solely from Twitter and engages with account holders directly. Similarly, dementia is a progressive condition, and although this study provides an important snapshot of the demographic characteristics of current Twitter account holders who identify themselves as having a diagnosis of dementia, it does not describe how the use of Twitter by people with dementia changes as their condition progresses. The use of longitudinal methods in future research could make it possible to examine this.

It is interesting to note that although descriptions of the experience of dementia varied, none of the account holders described themselves as 'suffering from' dementia, and only one used the term 'patient'. This may reflect the growing emphasis on personhood in dementia research and practice, which frames people

with dementia as individuals who are more than their diagnosis and can live well with the condition (Kitwood, 1997). Although it was beyond the scope of this study, future research could examine whether people with dementia are using Twitter to challenge stereotypical beliefs and further their social movement.

The majority of account holders described themselves as dementia advocates and/or were affiliated with a dementia working group. This suggests that these account holders could be using Twitter to facilitate advocacy and further their social movement, just like account holders who use hashtags relating to other issues (Bassett, 2015; Rosado & Marques, 2016). This finding is also consistent with research on the use of other social media platforms (e.g. blogs and forums) by people with dementia, which has also identified advocacy activities as important (Clare et al. 2008; Craig & Strivens, 2016).

Finally, more than half of the account holders did not present identities other than their dementia diagnosis, suggesting that these account holders could be using Twitter specifically for dementia advocacy, rather than general social contact. Despite this, it is still important to consider all aspects of identity that people choose to present. There has been a tendency for Twitter researchers who have examined health conditions to focus only on the diagnosis and not the other identities of account holders that co-exist with the diagnosis (e.g. parent, spouse, etc.; Page, 2012). Future research on the use of social media by people with health conditions, including dementia, must recognise the complexity of online identities and resist the temptation to reduce account holders purely to their diagnosis.



### **3.4.1 Limitations**

Although this study has demonstrated that people with dementia are active on Twitter, it does have some limitations. Firstly, Tweetcatcher uses Twitter's Search API, which only has access to a limited index of tweets and focuses on relevance, rather than completeness (Twitter, 2017b). Consequently, it is possible that not all account holders with dementia were identified and so the findings might not be representative of the total population of Twitter account holders who identify themselves as having a diagnosis of dementia. The Search API is, however, commonly used in Twitter research (e.g. Berry et al. 2017; Harris, Mueller, Snider, & Haire-Joshu, 2013; Hemsley et al. 2015). Tweetcatcher is also one of the most appropriate freely available data extraction tools (Brooker et al. 2016) and has been estimated to capture 74% of tweets (Ahmed & Bath, 2015). Although costly to use, future research could overcome this limitation by using Twitter's 'Firehose' Stream API to access 100% of tweets over a given period of time.

Secondly, this study only included Twitter accounts written in English and account holders who mentioned their dementia diagnosis in their 'bios', so the findings may not be representative of people with dementia who tweet in a language other than English or those with dementia who do not disclose their diagnosis in their profiles.

Finally, this study focused only on the profile information of account holders and did not examine the content of their tweets. As noted earlier, research examining the tweets of people with dementia could provide insight into how people with dementia use Twitter.

### **3.5 Conclusion**

This study clearly shows that people with dementia, with varying demographic characteristics and a range of dementia diagnoses, are active on Twitter. The majority of account holders reported 'living with' dementia, considered themselves dementia advocates, or were affiliated with dementia working groups, suggesting they could be using Twitter to facilitate an advocacy role. This finding is also supported by the absence of identity information beyond a diagnosis in more than half of account holders 'bios'. Future research could examine the profiles of people with dementia who tweet in languages other than English and those who do not disclose their diagnosis in their profiles. An analysis of the tweets of people with dementia would provide insight into how and why people with dementia use Twitter.

## **Chapter 4**

### **How People with Dementia use Twitter: A Qualitative Analysis**

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Talbot, C. V., O'Dwyer, S. T., Clare, L., Heaton, J., & Anderson, J. (2020). How People with Dementia use Twitter: A Qualitative Analysis. *Computers in Human Behavior*, 102, 112-119.

## 4.1 Rationale and Research Aims

Research on the use of Twitter by people with dementia is limited to just three preliminary studies (Cheng et al. 2018 Talbot, O'Dwyer, Clare, Heaton, & Anderson, 2018; Thomas, 2017), none of which provide a comprehensive overview of how people with dementia use Twitter. This preliminary research has focused on the 'bios' of people with dementia rather than their tweets (Talbot et al. 2018), used a small sample of only two people with dementia (Thomas, 2017), or grouped the tweets of people *with* dementia with those *affected by* dementia (e.g. friends or family members; Cheng et al. 2018). More research is therefore required to gain a better understanding of how people with dementia use the microblogging platform Twitter.

The aims of this research were to: (1) identify how people with dementia use Twitter; and (2) examine the extent to which people with dementia use Twitter to create and promote narratives related to their illness. This study was approved by the Human Research Ethics Committee of the University of Exeter Medical School.

## 4.2 Method

### 4.2.1 Sample

On 12<sup>th</sup> June 2017 16:42 (GMT), Tweetcatcher (Brooker et al. 2016) was used by the first author (CT) to identify tweets posted in the previous 24 hours that contained the search terms 'dementia' or 'Alzheimer'. The search was repeated every 24 hours for 30 consecutive days. A total of 416,826 tweets containing the terms 'dementia' or 'Alzheimer' were identified during this 30-day period. These tweets and associated

account holder data were imported into Microsoft Excel for analysis, and the profile descriptions of the account holders were searched for any evidence of a dementia diagnosis. Of the 217,623 individual account holders tweeting about dementia, 30 publicly identified themselves as having a diagnosis of dementia.

Account holders were sampled from this population of Twitter users who identified themselves as having dementia. Maximum Variation Sampling was used to recruit account holders. The purpose of using this sampling approach was to achieve representativeness and expand the range of differences within the sample, so that diverse variations of Twitter usage could be examined, and the patterns that cut across these variations could be identified (Patton, 2002; Palinkas et al. 2015).

To ensure the amount of data collected for this study was not unwieldy, we aimed to select a diverse sample of 12–15 account holders according to their type of dementia (Alzheimer's disease, vascular, Lewy body, frontotemporal, mixed, rare, not specified), location (UK and Ireland, Australia, North America), and sex (man, woman). A sampling framework was developed using these dimensions to accommodate as much variation as possible within the sample. Only accounts set to 'public' (i.e. that were not private) were included in the sample.

Using this framework, one man and one woman from each of the locations and dementia types were sampled. When a cell contained more than one account holder, random sampling was used to select a single account holder. Some cells in the sampling framework were not filled. Using this framework, 13 account holders were included in the initial sample. One account holder was excluded from the sample because of their involvement in the analysis. Instead, a different account holder with the same demographic variables was included in the sample. A second account holder had to be excluded due to a change in personal circumstances, and was

replaced with another individual with the same demographic variables. During the analysis, it became evident that one account was owned jointly by a person with dementia and their carer. Consequently, this account was excluded from the analysis. The final sample therefore comprised 12 account holders.

#### **4.2.2 Procedure**

Prior to data collection, the CT tweeted account holders to inform them that their tweets were being used for research purposes. Account holders were invited to direct message the researcher if they wanted to opt out of the analysis or ask questions about the research. On 2<sup>nd</sup> November 2017, CT used the data extraction software programme Tweetcatcher (Brooker et al. 2016) to identify tweets and retweets posted by the 12 account holders over the preceding six months. Tweets were collected before Twitter increased its character limit to 280 characters, when tweets were limited to 140 characters. A total of 11,527 tweets were collected, comprising 4,739 original tweets and 6,788 retweets. For the purpose of the present qualitative analysis, retweets without comments were excluded in order to focus on the more substantive tweets. For the purpose of this analysis, tweets aimed at specific account holders (i.e. tweets beginning with '@') were excluded from the analysis because the complete conversation was not available. A total of 2,774 tweets was included in the analysis. Some of the tweets identified by Tweetcatcher were incomplete. To obtain the full tweet, CT followed the hyperlink identified by Tweetcatcher to the original tweet and manually imported the full tweet into the dataset. Emojis were retained in tweets manually imported into the dataset. As well as identifying tweets, Tweetcatcher also collected hyperlinks to images posted by

account holders; however, only the tweet itself was analysed in this study (i.e. not the image).

#### **4.2.3 Analysis**

Tweets were analysed qualitatively using thematic analysis. The thematic analysis followed the steps identified by Braun and Clarke (2006, 2013): data familiarisation through reading a sample of tweets; generating initial codes and coding the entire dataset in NVivo; collating codes and relevant tweets together; examining codes to identify themes across the data; reviewing and refining the themes; and defining and naming the themes.

CT conducted the initial analysis. After the initial analysis was complete, the second author (SOD) reviewed the themes and a proportion of the coded tweets. Any issues raised by the SOD were discussed and addressed. The revised analysis was discussed with the rest of the research team and revisions were made to the analysis. Following this, coding was checked by the CT who searched the data in Nvivo to ensure the index had been systematically applied to the data. Errors in coding were corrected and any data that had been missed during the earlier stages of the analysis were coded. CT reread the tweets of three account holders to check the themes accurately reflected the data, and the themes were discussed with a person living with dementia to check that the findings were consistent with that person's experience. Codes and themes were organised into frameworks so comparisons could be made between account holders in relation to the demographics reported in their Twitter profile descriptions. A coding framework was developed throughout the course of the analysis to provide a clear trail of evidence.

The finalised codebook is reported in Appendix D. Direct quotes of tweets sent by account holders are presented in this paper to illustrate themes.

#### **4.2.4 Ethical considerations**

The British Psychological Society (2014) states that unless consent has been sought, observation of public behaviour must take place in public situations where people would expect to be observed by strangers. Twitter is considered a public platform and there is a general consensus among researchers that the content posted on Twitter can be used for research purposes (e.g. Moreno et al. 2013). In this study, informed consent was not obtained because tweets were posted on public accounts and, therefore, located within the public domain.

Ethical approval was obtained for the use of directly quoted tweets in this analysis. The use of direct quotes of tweets could potentially make account holders identifiable. To maintain respect for account holders, CT tweeted each account holder to inform them of the study and give them the opportunity to opt out of the analysis. This tweet was subsequently deleted after data collection. This approach has been successfully used in previous research (Anderson et al. 2017) and is consistent with recent research on account holders' attitudes towards using social media data in research (Fiesler & Proferes, 2018). Five account holders responded to the researcher's tweet asking for more information. None of these account holders asked to opt out of the analysis.

An advisory group comprising three people with dementia was consulted on the ethical framework and search terms for this study. CT was responsible for consulting this group. One member of this advisory group who has an active Twitter account



commented on the themes. This person agreed that the themes presented in this paper reflect her experience.

## 4.3 Results

### 4.3.1 Account holders

Four women and eight men were included in the analysis. Only four account holders reported their age, which ranged from 58 to 65. Six account holders were located in the United Kingdom, five in the United States of America and Canada, and one in Australia. Account holders had been on Twitter for an average of 6.08 years ( $SD=2.50$ , range: 2–9) and most ( $n=8$ ) self-identified as dementia advocates (i.e. they described themselves as advocates in their profiles or affiliated themselves with a dementia working group). Table 4.1 contains details of the account holders, using data collected from their profiles.

Table 4.1. *Participant demographics.*

ID	Sex	Age	Location	Type of dementia	Advocate	Years on Twitter
1*	M		UK	Alzheimer's	N	4
2	M		UK	LBD**	Y	6
3	M	60	UK	FTD***	N	5
4	W		UK	Rare	N	6
5*	M		UK	Not specified	Y	6
6	W	65	UK	Not specified	Y	2
7	W		Australia	Not specified	Y	9
8	M		USA	Alzheimer's	Y	9
9	M		USA	LBD**	Y	8
10	M		USA	Rare	Y	9
11	W	58	USA	Mixed	Y	2
12	M	58	USA	Not specified	N	7

\*Also participated in Study Three

\*\*Lewy body dementia

\*\*\*Frontotemporal dementia

### **4.3.2 Themes**

Six themes were generated from the data: nothing about us without us; collective action; experts by experience; living with dementia not suffering from it; community; and stories of dementia. These themes are discussed below with direct quotes of tweets to illustrate each theme.

All themes except for stories of dementia concern the collective identity of account holders as a result of their diagnosis, with their tweets considered to be contributing to a wider social movement about, for, and by people with dementia. In comparison, stories of dementia concern the individual identities account holders communicate through tweets that document their personal experiences. Most account holders used Twitter for collective action and to share their stories of dementia, as illustrated in Table 4.2. After the sample was selected and tweets were collected, it became evident that one account holder (ID=11) only retweeted information and did not produce any individual tweets.

Table 4.2. *The mapping of each theme within account holders' tweets.*

Theme	Account holder ID											
	1	2	3	4	5	6	7	8	9	10	11	12
Nothing about us without us			X		X		X	X	X			
Collective action	X	X	X		X	X	X	X	X	X		X
Experts by experience	X	X			X							X
Living with dementia not suffering from it	X	X			X		X		X			X
Community	X				X		X	X	X			X
Stories of dementia	X	X	X	X	X	X	X	X	X	X		X

#### **4.3.2.1 Nothing about us without us**

Five account holders used Twitter to represent the needs and experiences of people with dementia. Four of these account holders identified themselves as dementia advocates, which suggests that representation is an important part of advocacy. Some advocates ( $n=2$ ) used Twitter to contribute their lived experiences to conference hashtag discussions and to hold local NHS trusts and conference organisers publicly accountable when the voices of people with dementia were not represented ( $n=2$ ). One account holder, for example, used Twitter to comment on a lack of representation of people with dementia on a conference panel.

*One half of the consumer coin is there - a carer. The other half is obviously missing in action*

Advocates also tweeted positively when people with dementia were adequately represented. Through their use of Twitter, these advocates were able to maintain a voice in discussions about them and potentially evoke social change by commenting publicly on a lack of representation.

*Thank you @DementiaAustralia for creating the change #onthespot #beTheChange2017 by making room 4 a person with dementia to join the panel*

#### **4.3.2.2 Collective action**

Ten account holders tweeted about collective actions such as fundraising, political lobbying, and raising awareness. Almost all the self-identified dementia advocates used Twitter for fundraising ( $n=7$ ) and political lobbying ( $n=6$ ), which could be considered an important part of advocacy. Both advocates ( $n=3$ ) and non-advocates ( $n=2$ ) used Twitter to raise awareness, suggesting that this is important for both groups.

*June is Alzheimer's and Brain Awareness Month. Get involved, be part of the cure. @alzassociation #ENDALZ*

Account holders largely raised funds for established organisations (e.g. the Alzheimer's Association) rather than individuals (e.g. GoFundMe pages), suggesting that these advocates see themselves as part of a larger movement. Almost all fundraising was for dementia-specific charities, indicating that these advocates identify with a dementia-specific movement, which occasionally includes other health conditions.

*Buy a Walk to Remember T-Shirt by July 24th to help us raise funds for our Walk to Remember Friend Raiser event [customink.com/fundraising/wa...](http://customink.com/fundraising/wa...)*

Seven account holders shared petitions on Twitter and engaged with politicians. Through their political lobbying, these account holders sought to influence the policies that affect their lives by gaining support for their cause and engaging with people who make important decisions about the lives of people with dementia.

*I've united with @alzheimerssoc to end the #DementiaTax. Sign the petition now and call on the Government to act*

#### **4.3.2.3 Experts by experience**

Four of the account holders used Twitter to educate others about dementia, thus identifying themselves as experts by experience. These account holders tweeted about a range of topics, such as symptoms, diagnostic information, dementia-friendly communities, advice on caring, and tips for interacting with people living with dementia.

*#DiverseAlz It annoys me is when I hear "People who have Alzheimer's or dementia" what's that about? Alzheimer's is a type of dementia*

Advocates ( $n=2$ ) and non-advocates ( $n=2$ ) used Twitter to educate others, indicating that education about dementia is important to both groups. Account holders used Twitter to educate carers, health care providers, researchers, and members of the public. By educating other account holders about dementia, the account holders in this study identified themselves as authority figures who are knowledgeable about their condition and able to use their experiences to educate both the general public and those who are traditional sources of knowledge (e.g. clinicians, researchers). All of the account holders who used Twitter to educate others about dementia were men. While it is important that people are educated

about dementia, an absence of female voices may be leading to a lack of education about the needs and experiences of women.

*A pilot decision-making tool for GPs | YoungDementia UK Do look at this...it's really good.*

#### **4.3.2.4 Living with dementia, not suffering from it**

Six account holders tweeted about stigma and the need for more positive language around dementia. Advocates ( $n=4$ ) and non-advocates ( $n=2$ ) tweeted about stigma, suggesting this is an important issue for both groups. These account holders rejected negative language used to describe dementia, such as 'suffering' and 'demented', and language that framed them as a burden.

*#DiverseAlz I don't want to read/hear words which implies how much of a 'burden' we are or how challenging our behaviour is for loved ones.*

Two account holders made comparisons between the stigma of other health conditions (e.g. cancer) and dementia. These tweets highlight an inequality between dementia and other health conditions, such as cancer, where people with dementia are sometimes the subject of jokes and treated as sub-human

*#DiverseAlz Can you imagine a comedian standing up and making a joke about someone with cancer?*

Three account holders tweeted suggestions for appropriate language and two advocates held people who used stigmatising language publicly accountable. By challenging stereotypical beliefs and negative language, these account holders were seeking to change public perceptions of dementia and reaffirm their identities as people who can live well with the condition. Five of the six account holders who

tweeted about stigma were men, so it is difficult to determine whether women with dementia who use Twitter also experience this kind of stigma.

*@abcnews Oh, and NOT calling us #sufferers would be respectful.  
@AlzheimersAus should have made sure that word was NOT used &  
@abcnews knows better.*

#### **4.3.2.5 Community**

Six account holders tweeted support to other people with dementia and carers. Because account holders also supported carers, this suggests that this online community includes people who have or are otherwise affected by dementia.

*#ENDAlz @alzheimersmanh @alzassociation Do you know a caregiver  
please give them a call, let them know you are there for them. HELP THEM!!*

Both advocates ( $n=4$ ) and non-advocates ( $n=2$ ) tweeted messages of support, indicating that Twitter could be a source of support for both groups. Only one account holder, a non-advocate, tweeted direct support to a person struggling with symptoms.

*I told you I'm speaking from experience and you can learn to tame it, make sure  
you talk about how you feel even if it writing it down 😊*

Advocates tweeted messages of congratulations to other advocates for giving talks, setting up working groups, writing articles, and winning awards, but did not give direct support to people struggling with symptoms. This could be because advocates are more focused on promoting their cause, because this level of support takes place privately (e.g. over direct message), or because tweets aimed at specific people were not included in the analysis.

*I've read your story on the Elder interview and it's inspirational so you keep  
telling it especially to those newly diagnosed*



Account holders tweeted information about dementia cafés and Dementia Engagement and Empowerment (DEEP) group meetings. These tweets highlight that DEEP group meetings are a valuable source of support. People with dementia could be tweeting about this initiative to support others with a diagnosis. By tweeting information about local DEEP group meetings, these account holders could also be improving their own lives by increasing their number of offline social connections.

*New DEEP group mtg first Thursday of month. Social group for people with dementia, esp but not only young onset*

Some account holders ( $n=2$ ) also acknowledged the importance of Twitter as a source of support, highlighting the value of this support network for people with dementia following a diagnosis to reduce feelings of loneliness and isolation.

*I'm lucky I got/get the right help & support which prevented me from going into a shell & I get great support here on Tweeter from you all 😊😊*

#### **4.3.2.6 Stories of dementia**

Almost all account holders ( $n=11$ ) tweeted about their personal experiences of dementia. Advocates ( $n=7$ ) and non-advocates ( $n=4$ ) tweeted about positive aspects of their lives, such as publishing books, engaging with advocacy work, taking part in research, and passing a driving assessment. By sharing their positive life experiences and documenting life after a diagnosis, these account holders constructed a narrative that identified them as people living well with the condition.

*Passed my driving assessment today. Just the DVLA to confirm now. So one more year of driving now. Dementia not taking me off road yet.*

Seven advocates documented their offline advocacy work, suggesting that evidencing offline advocacy work is important for creating an online advocate identity.

*All ready for another three mornings talks to graduate nurses at Northumbria University, on living with dementia starting tomorrow.*

Only four account holders shared negative experiences of living with dementia. One account holder, for example, described experiencing problems with memory. While this shows that some people with dementia are using Twitter to discuss negative experiences, the dominant narrative on Twitter was one of positivity and living well.

*Not a good week at all, and have just realised how bad my memory has been. It's been a shock to the system to be told what I've been like.*

Account holders ( $n=6$ ) shared links to other social media platforms (e.g. personal blogs, YouTube, Facebook, Soundcloud) where they also documented their experiences of dementia. It seemed that people with dementia were using these other social media platforms to share their stories of dementia in greater detail than is available within Twitter's (then) character limit, including the more negative experiences.

*Please visit my blog site to learn about my journey living with Alzheimer's disease.*

#### 4.4 Discussion

Researchers have started to examine the use of social media by people with dementia (Craig & Strivens, 2016; Kannaley et al. 2019; Rodriguez, 2013), but little is known about how people with dementia use Twitter. This study makes a unique contribution to the literature by specifically examining the tweets of people with dementia. Six themes were generated from the tweets of people with dementia: nothing about us without us; collective action; experts by experience; living with dementia not suffering from it; community; and stories of dementia. Each of the themes except for 'stories of dementia' concerns a collective identity resulting from the diagnosis. In their tweets, these account holders collectively identify with a wider social movement which is focused on making social change to improve the lives of people with dementia. Some account holders also constructed individual identities on Twitter by sharing their personal experiences of dementia, and in these narratives, they presented themselves as dementia advocates and people who were living well with dementia.

The majority of account holders' tweets focused on a shared collective illness identity, rather than their personal experiences. Previous research has shown that dementia advocates are creating networks offline, developing a collective identity, and becoming politicised (Bartlett 2014a, 2014b). The findings of this study suggest that this is also happening on Twitter where people with dementia are using the platform to create networks and support their advocacy work. More than half of the advocates in this study used Twitter for representation, fundraising, political lobbying, and documenting their offline advocacy work, suggesting that these activities are an important part of online advocacy. Although Twitter advocacy work does not seem to be replacing offline advocacy, it is providing dementia advocates with an additional

platform through which they can share their messages with a wider audience and challenge public perceptions of dementia. Future research conducted with dementia advocates should, therefore, also account for their online advocacy work.

In this study, the use of Twitter by people with dementia was highly political, as evidenced by tweets about representation and political lobbying. This level of political engagement has not been evident for people with dementia on other social media platforms (Craig & Strivens, 2016; Kannaley et al. 2019; Rodriquez, 2013), which highlights the uniquely political nature of Twitter and is consistent with previous research showing that people with other chronic illnesses and members of the public use Twitter to influence policymaking and draw attention to social issues (Granger, 2013; Highfield, 2016). It is unclear whether people with dementia have seen any societal changes as a result of their online advocacy, but future qualitative research conducted with people with dementia could examine this.

The findings of this study suggest that people with dementia are using Twitter to become visible and broadcast an advocate and positive perspective on living with dementia to a wider audience. This finding is mirrored in research examining the use of Twitter by people with communication disabilities who have used Twitter to communicate their experiences to a wider audience (Hemsley & Palmer, 2016; Hemsley et al. 2015). Like people with cancer, the findings of this research suggest that people with dementia are using Twitter to influence societal change through their online collective action (Granger, 2013). In comparison to people with other chronic health conditions, such as depression (Berry et al. 2017) and diabetes (Liu et al. 2016), the use of Twitter by people with dementia appears to be more political and focused on the creation and promotion of a social movement (Berry et al. 2017). This reflects a recent emphasis within policymaking that has identified dementia as a

political priority (Department of Health, 2016). People with dementia could also be more motivated to change perceptions because they often face the double stigma of dementia and old age (Milne, 2010). By challenging perceptions of dementia on Twitter and educating others about the condition, people with dementia may be able to change how others view them, promote their social inclusion, and uphold the personhood and citizenship of those living with a diagnosis.

The findings of this study suggest that there is a community of people with dementia who are using Twitter to support one another as well as those affected indirectly by dementia, supporting Cheng and colleagues' (2018) finding that those affected by dementia are using Twitter to access support. Following a diagnosis, many people with dementia also experience a loss of identity (Naue & Kroll, 2009); however, membership in online Twitter communities might help to reinstate a sense of identity among people with dementia, provide social connection, and potentially reduce feelings of isolation and loneliness that often follow a diagnosis (Spreadbury & Kipps, 2017). Future research could examine the benefits of using social networking sites for people with dementia.

In this study, it was mostly men who challenged stigma and educated others about dementia on Twitter. Consequently, the challenges faced by women with dementia are not being discussed on Twitter, which might further perpetuate the marginalisation experienced offline by this group (Mears, 2018). It is also consistent with the fact that men are overrepresented as advocates in the dementia rights movement offline (Ludwin & Parker, 2015). So, while Twitter could be providing a way for some people with dementia to have their voices heard, challenge stereotypes, and re-affirm their identities, it may not be doing this for all groups of people with dementia. It is also unclear from the findings of this study, given a lack of

demographic data, whether the voices of people with dementia from other marginalised groups (e.g. Black, Asian, and minority ethnic; LGBTQ+) are represented on Twitter. Research which engages with marginalised groups of people with dementia could examine their use of Twitter and the challenges they face in being heard online.

One account holder in this study only retweeted information and did not produce any individual tweets. A similar finding was identified in Hemsley and colleagues' (2015) research on the use of Twitter by people with communication disabilities. While this could simply be how the account holder has always used Twitter, it may also be a reflection of advancing symptoms of dementia. Account holders who use social media to view information but not post original content have been referred to as 'lurkers' in previous social media research (see Edelman, 2013; Sun, Rau, & Ma, 2014); however, it seems unhelpful to apply the negative connotations associated with 'lurking' to people with dementia. Instead, becoming less active on Twitter but continuing to be involved by retweeting information could be a valuable source of social connection and self-expression for some people with dementia as their symptoms progress. Future research which analyses the use of Twitter by people with dementia at different stages of the disease trajectory could help to elucidate the impact of progressive illnesses on the use of social media.

While the account holders in this study tended to focus on a collective social movement, they also used Twitter to document their personal experiences of living with dementia. The findings of this study suggest that people with dementia are using Twitter to communicate their experiences of illness in less than 140 characters, supporting Thomas' (2017) finding that the tweets of people with dementia provide important information about their experiences. Illness narratives have traditionally

been considered to be long-form expressions (e.g. journal entries), but the findings of this study suggest that narratives can be created in shorter messages over time. Taken together these 'short stories' (Page, 2012) form an illness narrative through which people with dementia are communicating their experiences to the world. The lived experience of dementia shared on Twitter may be qualitatively and quantitatively different from that shared in offline spaces. Qualitative researchers could, therefore, analyse these tweets about personal experiences to gain further insight into the lived experience of dementia. Likewise, while thematic analysis has traditionally been applied to longer pieces of text (e.g. Anderson et al. 2017; Toms et al. 2015), this study shows that it can also be applied to micro texts that combine over time to create longer narratives.

The dominant narrative across all of the tweets analysed in this study is one of advocacy and living well. Other narratives, such as those of people who are struggling with their symptoms, were notably absent from the data. This is consistent with the traditional illness narrative literature, in which there is a focus on recovery (Garden, 2010). It is possible that a lack of negative experiences being present in account holders' tweets could be an artefact of people who are living well with dementia being those who choose, or are able, to interact on Twitter. This finding could also be due to account holders' use of Twitter to produce social change, where tweeting about the negative aspects of their lives could further perpetuate the stereotypes they are trying to challenge. Negative stories of dementia might be present in more private digital spaces, such as Twitter's direct message or closed groups on other social media platforms. Researchers could engage with people with dementia to examine why they focus on the positive in their tweets and identify which digital spaces they use to document their negative experiences.

The account holders in this study often shared links to other social media platforms where they also shared their experiences of living with dementia. By managing multiple social media accounts, these account holders demonstrate an ability to use technology, thus challenging stereotypical assumptions of dementia. It is clear that the account holders in this study cannot be viewed as victims who experience a loss of self and 'a living death' (Fontana & Smith, 1989; Cohen & Eisdorfer, 1986; Woods, 1989). People with dementia could be using these different forms of social media for a variety of reasons, revealing different aspects of their identities on each platform. While the findings of this study show the use of Twitter by people with dementia is focused on furthering a collective social movement, blogs written by people with dementia (Kannaley et al. 2019), for example, might contain more detailed information about personal identities and everyday experiences than is possible on Twitter due to the character limit. Social media platforms do not operate in isolation, so in future researchers could analyse the use of different social media platforms by people with dementia to gain a comprehensive understanding of their identities and how these online identities intersect.

#### **4.4.1 Limitations**

While this study provides an in-depth examination of the tweets of people with dementia, it does have some limitations. Firstly, conversational tweets were not included in this analysis. Conversations are an integral aspect of Twitter and it is likely that these conversations contain important information about how people with dementia use Twitter. These conversational tweets could contain information about who people with dementia interact with on Twitter as well as the support they receive. Future research could examine conversational tweets to gain a more



complete understanding of how people with dementia use Twitter. Likewise, retweets comprised a large proportion of the data but were excluded from the analysis. Future research examining the retweets of people with dementia could identify what information people with dementia are promoting on Twitter and the credibility of this information.

The tweets analysed in this study were all publicly available data; however, the public side of Twitter is only one aspect of an account holder's experience. Conversations which take place in private (i.e. via direct message) might be used by people with dementia for other purposes, such as private support. Future research could engage people with dementia to examine their reasons for having private conversations on Twitter.

Only four women were included this study, meaning that any firm conclusions about gender are limited by the small sample size. The different experiences of men, women, and diverse groups of people with dementia should therefore be considered in future research.

It was not possible to verify the diagnosis of account holders in this study, which means that we did not have information about their symptoms, stage of dementia, or quality of life, which could have influenced how they use Twitter. In research examining the use of Twitter by a person with terminal cancer, for example, Taylor and Pagliari (2018) found that the person focused more on social relationships and support during the dying phase than in the other cancer phases. This could also be the case for people with dementia. Future research could examine change in Twitter usage by people with dementia as the disease progresses and the impact this has on their identity.

In addition, the findings of this study only focus on the content of public tweets which were largely positive. People with dementia could experience relational and practical problems when using Twitter, such as trolling and issues with accessibility. One account holder (ID=11), for example, only retweeted information. This finding highlights that some people with dementia might find it easier to retweet information than write personal tweets. In future research, reflective interviews could be conducted with people with dementia to identify the problems they face when using Twitter, which could inform platform developers about how they can make social networking sites more accessible for people with dementia.

#### **4.5 Conclusion**

In conclusion, people with dementia are using Twitter to identify with a collective social movement focused on producing social changes which improve the lives of people with dementia. These account holders are using Twitter to fight for representation, fundraise, lobby politicians, raise awareness, challenge stigma, educate others, and provide support. People with dementia are also constructing personal identities on Twitter by documenting their personal experiences. These narratives tend to focus on dementia advocacy and living well rather than the negative aspects of living with dementia. Future research could examine what motivates people with dementia to use Twitter, the challenges they face, and how their Twitter use changes as their symptoms progress.

## **Chapter 5**

### **The Experiences of People with Young-onset Dementia who use Twitter: A Thematic Analysis**

## **5.1 Rationale and Research Aims**

The findings of existing research on the use of Twitter by people with dementia suggests that they have used Twitter for advocacy, support, educating others, challenging stigma, and documenting experiences (Cheng et al. 2018; Talbot et al. 2018, 2020; Thomas, 2017). While this research has provided initial evidence on the value of Twitter for people with dementia, it has been informed predominantly by the tweets they post and researchers have not yet directly explored the perspectives and lived experiences of people with dementia who use Twitter. This prior research has also tended to focus on the positive ways in which people with dementia use Twitter, and researchers have not yet explored the challenges people with dementia face when using the microblogging site. The aim of this study was to explore the perspectives of people with dementia in order to gain an understanding of how and why they use Twitter, what benefits this confers, and the challenges they face.

## **5.2 Method**

### **5.2.1 Design**

A qualitative multiple case-study approach was taken (Yin, 2003, 2009), whereby people with dementia took part in in-depth interviews that explored their use of Twitter. Measures of cognition and functional ability were also included in the research design because these factors might be associated with differential patterns of Twitter usage. It was therefore important to take these measures into account when interpreting participants' experiences. This study was approved by the Human Research Ethics Committee of the University of Exeter Medical School.

### **5.2.2 Recruitment**

We aimed to recruit a sample of 10-15 people, consistent with recommendations for interview studies that aim to identify patterns across data and describe a shared behaviour among a relatively homogenous group (Guest et al. 2006). Participants were sampled from a population of Twitter users with dementia who were identified in a previous study (Talbot et al. 2018). In that preliminary study, Tweetcatcher (Brooker et al. 2016) was used to locate tweets posted during a 24-hour period that contained the search terms 'dementia' and 'Alzheimer'. The search was repeated every 24 hours for 30 consecutive days. Tweets and associated account holder data were imported into Microsoft Excel and the profile descriptions were then searched for any evidence of a diagnosis. For practical reasons, the sample for this study was limited to account holders located in the UK.

Thirty account holders publicly identified themselves as having a diagnosis of dementia, of whom 15 were located in the UK. Fourteen of these account holders were tweeted by the first author informing them of the research; one person was not contacted because she had already been involved as an advisor to the study. Six account holders responded to the tweets and five of them consented to take part in the study.

To achieve a larger sample, the first author (CT) also searched Twitter to identify and contact additional account holders who may not have been using Twitter during the original searches. This search was conducted by inputting "person with dementia", "living with dementia", and "dementia advocate" into the search bar of Twitter. CT also scrolled through the tweets of dementia advocacy accounts, such as @DementiaVoices and @Innov\_Dementia, to identify additional account holders

who were mentioned in the tweets posted by these accounts but not located in the initial searches.

A snowballing approach was also used, with existing participants and people with dementia who were advisors to the study. These people were asked if they knew anyone with dementia who was using Twitter and might be interested in participating in the research. Using these additional sampling techniques, six more people with dementia consented to take part in this study. The final sample consisted of 11 people with dementia. After initial contact on Twitter, all remaining contact regarding recruitment into the study took place via email and telephone. One participant dropped out of the study after the initial meeting with the researcher because his health deteriorated. This participant consented to his data from the initial meeting being used in the research.

### **5.2.3 Interviews and measures**

In-depth interviews were conducted with people with dementia at three timepoints across a period of one year. All interviews were conducted by CT. After the initial interview, follow-up interviews took place six- and 12-months later. The main focus of interviews at six- and 12-month follow-up was change in usage of Twitter; however, revisiting participants at these timepoints also allowed for clarification of responses from the initial interview and opportunities to ask additional questions about their experiences, which arose from interviews conducted with other participants at initial interviews. All of the initial interviews were included in this analysis as well as responses to clarifying questions at six- and 12-month follow-up interviews. Information about changes in participants' use of Twitter over time was not included in this analysis and is reported in Chapter 6.

Interviews were split into two parts. In the first part of the interview, participants were asked about their experiences of using Twitter, with the discussion guided by a semi-structured interview guide. Interview guides were developed by the first author for each individual timepoint (see Appendix J-L). Each interview guide was reviewed by the rest of the research team and by a person with dementia to ensure relevant topics were being covered, questions were being asked in an appropriate and adaptable sequence, and language was accessible. The first author conducted a pilot interview with a person with dementia to review the interview guide for the initial interviews. Following this, amendments were made to the guide to add, remove, rephrase, or change the anticipated order of questions as appropriate. The initial interview guide focused on reasons for joining Twitter, reasons for using Twitter, self-presentation on Twitter, interactions with other account holders, and barriers to using Twitter.

The second part of the interview was an adapted version of the scroll back method, which had previously been used with Facebook data (Robards & Lincoln, 2017). Participants were asked to scroll through their social media posts and discuss them with the researcher, thus prompting further, focused discussion about their use of social media. In this study, the first author adapted the scroll back method by printing and presenting participants with a random sample of 10 tweets they had posted in the previous six months, including retweets. Participants were asked to explain why they sent each tweet, what they hoped to achieve by posting the tweet, how they felt at the time they sent the tweet, and what type of reaction the tweet provoked.

As well as taking part in interviews, participants completed the self-rated version of the Instrumental Activities of Daily Living scale (IADL; Lawton & Brody, 1988) as a

measure of functional ability. The self-rated version of the IADL scale assesses functioning across nine dimensions: preparing own meals; using the telephone; shopping for groceries; getting to places out of walking distance; doing housework; doing handyman work; washing clothes; managing money; taking medications. A trichotomous response scale was used (1 = unable; 2 = able with help; 3 = able without help) with a possible total score between 9 and 27 where lower scores indicate greater dependence.

The Mini Mental State Examination (MMSE; Folstein et al. 1975) was also administered to the participants as a measure of cognition. The MMSE takes 5–10 minutes to administer and comprises 30 questions that assess cognitive function across various domains, including orientation, language, registration, memory, calculation, and visual-construction. Total scores on the MMSE can range from zero to 30, with lower scores indicating greater impairment.

#### **5.2.4 Procedure**

Participants completed the self-rated version of the IADL scale before interviews. Following this, CT met participants at their homes or a place of their choosing. The MMSE was then administered by CT. During MMSE administration, at each timepoint, all participants completed the serial sevens calculations task and therefore did not complete the task where they are asked to spell “world” forwards and backwards. Following this, semi-structured interviews (including the scroll back method) were conducted with participants at either their own homes or a place of their choosing. Interviews were recorded using a digital device, transcribed verbatim by CT, and anonymised. When the speech of participants was difficult to understand, intelligent verbatim transcription was used to edit out fillers and repetition that



detracted from the content of the data. Interviews ranged in length from 35–80 minutes (not inclusive of the time taken to administer the MMSE and IADL scale). At the end of the data collection phase of the study, Twitter data were collected from the profiles of participants, including total number of tweets posted, number of followers, and number following.

### **5.2.5 Analysis**

Interviews were first analysed qualitatively using Braun and Clarke's (2006; 2013) approach to thematic analysis. Responses at the initial interview, clarification questions at six- and 12- month follow-up interviews, and the data collected using the scroll back method were analysed together.

CT familiarised herself with the data by reading anonymised interview transcripts to immerse herself in the data and mark ideas for coding that she could return to in subsequent phases of the analysis. The second author (SOD) also familiarised herself with the data by listening to all of the interviews, and anonymised transcripts of two interviews were reviewed by the third (LC) and fourth (JH) authors. Initial codes were generated by the CT and the entire dataset was coded using QSR International's NVivo 11 software. Following this, codes and relevant data extracts were collated and examined to identify themes across the data. Themes were reviewed by the research team and revisions were made by CT. Themes were then defined and named. Coding was subsequently checked by the CT who searched the data in NVivo 11 to ensure all data had been systematically coded. Any errors in coding were corrected and any data that had been missed during the earlier stages of the analysis were coded at this point. Coding, theme names, and definitions were

reviewed by the three co-authors and amended as appropriate. The final version of the coding index is reported in Appendix N.

A description of the themes was emailed to three participants who were chosen at random, and one person with dementia who advised on the project, to check that the findings were consistent with their experiences. CT was responsible for liaising with this group of people. This group of people agreed that the findings were consistent with their experiences and made no suggestions for changes to themes. After the data were coded and themes finalised, participant demographics, Twitter and interview data, and measures of cognition and functional ability were tabulated to identify commonalities and differences across participants.

## **5.3. Results**

### **5.3.1 Participants**

Eleven people with dementia (eight men and three women) were included in the sample. Although we did not specifically aim to recruit people with young-onset dementia, only people with young-onset dementia participated in this study. The average age of participants was 54 years (range = 48–66 years). Participants were all of white British origin. Most participants had managerial or professional occupations before they retired from work. Six participants provided information about their level of education. Four of these participants had a university degree, one participant had a Level 4 National Vocational Qualification (NVQ), and one participant had college level qualifications. All participants had engaged in offline advocacy before taking part in this research, such as speaking at conferences, lobbying politicians, and educating students about lived experience. The most

frequent diagnosis was mixed dementia ( $n=4$ ), followed by vascular dementia ( $n=3$ ), Alzheimer's disease ( $n=2$ ), and posterior cortical atrophy (PCA;  $n=1$ ). One participant was unsure of her specific diagnosis.

Participants' scores on the MMSE at the time of the first interview ranged from 14 to 29 and IADL scores ranged from 12 to 27, consistent with mild to moderate dementia (Folstein et al. 2001). Twitter data were not collected for one participant (ID=P7) because he dropped out of the study after the initial interview. On average, participants had 2,881 followers (range = 79–12,113 followers), followed 2,172 other account holders (range = 68–12,337), and had posted 19,203 tweets (range = 128–65,382). Table 5.1 describes the sociodemographic characteristics of the sample, along with information about their health status and Twitter accounts.

Table 5.1. *Characteristics of the participants.*

ID	Sex	Age	Age at diagnosis	Ethnicity	Previous occupation	Level of education	Type of dementia	MMSE	IADL	Followers	Following	Tweets posted
1*	M	66	63	White	School business manager	University degree	Mixed	29	23	2184	1,050	8,190
2*	M	65	57	White	Senior manager	NVQ (Level 4)	Alzheimer's	16	12	7681	5,016	54,403
3	W	48	45	White	Nurse	University degree	Posterior Cortical Atrophy	28	26	2904	1,350	42,600
4	M	65	56	White	Police officer	-	Vascular	19	12	776	169	5,523
5	M	57	51	White	Property manager	College education	Mixed	14	13	12,113	12,337	65,382
6	M	55	54	White	Clinical support worker	University degree	Mixed	24	21	1,180	1,084	8,966
7	M	59	54	White	Local government officer	-	Vascular	19	14	-	-	-
8	W	59	53	White	Business support manager	University degree	Unknown	29	27	442	149	214
9	M	66	57	White	Lorry driver	-	Vascular	24	20	79	68	128
10	W	64	59	White	Horticulturist	-	Mixed	17	21	1,094	384	5,952
11	M	53	50	White	Business owner	-	Alzheimer's	20	16	366	113	674

\*Also participated in Study Two

### 5.3..2 Themes

Six themes were generated through the analysis. People with dementia were found to use Twitter for community, as a springboard, as a diary, for expression, as a soapbox, and to enhance self-worth. Each of these themes are discussed below with a selection of anonymised quotes from interviews with participants to illustrate the findings. In these extracts, 'I' refers to the interviewer and the participant's unique identifier (e.g. 'P3') is used to refer to the interviewees. Potentially identifiable information in quotations has been removed and indicated using [substitute information]. Pauses in speech are indicated by the use of '...'. Table 5.2 provides an overview of each theme and Table 5.3 shows how the themes were spread across the participants' accounts.

Table 5.2. *Overview of themes.*

Theme	Description
Community	Using Twitter for social connection and support
Expression	Using Twitter to overcome the challenges of offline communication
Diary	Using Twitter to record and look back on experiences
Soapbox	Using Twitter for advocacy
Springboard	Using Twitter to increase offline social connections and access information about offline activities
Self-worth	Using Twitter to maintain a sense of purpose

Table 5.3. *Representation of the themes in individual participants' accounts.*

Theme	Participant ID										
	1	2	3	4	5	6	7	8	9	10	11
Community	X	X	X	X	X	X	X		X	X	X
Expression		X	X		X	X	X			X	X
Diary		X	X		X				X		X
Springboard	X	X	X	X	X	X	X	X	X	X	X
Soapbox	X	X	X	X	X	X	X	X	X	X	X
Self-worth	X	X	X		X	X				X	X

### **5.3..2.1 Using Twitter for community**

As shown in Table 5.3, almost all participants used Twitter for social connection, which included keeping in touch with friends and advocacy groups, giving and receiving peer support, and making new friendships. Four participants (P1; P6; P7; P9) discussed their use of Twitter in reference to a lack of post-diagnostic support, and two participants (P2; P10) discussed their use of Twitter in relation to the feelings of isolation they experienced immediately after being diagnosed with dementia. Following these experiences, participants used Twitter to connect with a wider community of people living with dementia, access peer support, learn from others living with the condition, and connect with carers, researchers, and advocacy and support organisations. For three of these participants, Twitter was a “*lifeline*” (P2; P3; P7).

P6: *I went to work for the last time in September, then I was signed off work and I retired in February. But there was nothing there...so you're just left...so I thought I'd have a go on Twitter, and I found a lot of people in the same situation as me, and we started learning from each other...so it's helped me to start finding my way again*

Seven participants (see Table 5.3) reported following and communicating with other people with dementia on Twitter to combat feelings of isolation, which was particularly important for participants who lived in rural areas or on their own. Despite the majority of account holders using Twitter to access peer support ( $n=9$ ), two participants (P8, P9) did not use Twitter for this reason. These two participants mainly used Twitter for campaigning and documenting experiences. Both these participants reported having good offline support networks, which might be another reason why they did not use Twitter for support. In addition, these two participants had relatively high MMSE and IADL scores suggesting that Twitter might be a more valuable source of support for those with more advanced symptoms.

P11: *I think it is so good to have the world at your fingertips, and to keep connected with people, because if I can't drive, which I can't now, and I'm here in this environment, my wife is at the moment doing some stuff for her mother, and if [name] wasn't here I'd be on my own*

While Twitter might be a good source of post-diagnostic support, particularly for those who live alone or in rural areas with access to the internet, and for those who do not have offline peer support networks, support is not the only reason people with dementia use Twitter.

### **5.3..2.2 Using Twitter for expression**

As described in Table 5.3, seven participants used Twitter for self-expression. Four of these participants (P2; P5; P6; P10) said they found it easier to communicate on Twitter than in person or on the telephone because they could communicate at their own pace, and check the spelling and wording of tweets. These participants said they were concerned about making mistakes and forgetting words when they had conversations offline. Two participants (P7; P10) also felt they could express themselves on Twitter without being interrupted, which happened often during offline communication. Being able to express themselves on Twitter was “*therapeutic*” (P2; P3) for two participants because it allowed them to speak openly about their experiences without fear of judgement. This finding suggests that social media platforms might provide a powerful way for the wider community to engage with people with dementia whose voices might otherwise not be heard. This is particularly important for people with dementia who often face several barriers when trying to express themselves, such as having people speak over them.

P7: *Twitter, it's revolutionary in as much as you have this media where people can be heard for the first time. If I'm typing away, nobody can interrupt me... You can't do that anywhere else. You couldn't have that in conversation. And that is very difficult for people with dementia because if you're talking and somebody interrupts you mid-flight then it's gone*

Participants also used other social media platforms to express themselves, such as Facebook and blogs. Five participants (P2; P3; P5; P6; P10) commented, however, that the character limit of tweets facilitated self-expression. One of these participants said “*I can't do Facebook because there's too many. You know you put too many sentences together or something like that, whereas Twitter it's to the point*” (P2). This participant had one of the lower scores on the MMSE and reported experiencing



problems with concentration. The character limit of tweets, however, allowed him to focus on what he was trying to communicate. This suggests that the short-text nature of tweets might facilitate self-expression in people with dementia, particularly for those who are experiencing difficulties with concentration or speech.

Four of the seven participants (P2; P3; P5; P6) who used Twitter for self-expression posted the greatest number of tweets in the sample. The relatively large number of tweets posted by these participants might reflect the importance of self-expression for these participants. In addition, participants who used Twitter to express themselves tended to have relatively lower IADL scores and MMSE scores. These findings indicate that Twitter might be a particularly valuable tool for people with more advanced symptoms, whose voices might not be heard offline.

In contrast, three participants (P1; P3; P6) felt that the character limit of Twitter sometimes hindered self-expression, whereas blogging facilitated more in-depth communication. These participants had comparatively higher MMSE and IADL scores than the rest of the sample, which might explain why they were able to manage the cognitive demands of blogging. These participants said that when they published a blog, they would always promote it on Twitter. This indicates that some people with dementia are using various types of social media to express themselves, and are using Twitter to guide their followers to other platforms. While tweets might contain some information about the experiences and perspectives of people with dementia, blogs written by people with dementia provided an opportunity for more detailed discussions of their experiences.

P3: *I can't talk about everything. I haven't got enough characters on Twitter to talk about everything, so I can put more words on my blog and then I*

*can just transfer that over so I can then share my blog page on my Twitter*

Two participants (P3; P10), both women, felt they were able to express themselves on Twitter because their friends and family did not have Twitter accounts, which meant that they could share their experiences without worrying about the reactions of friends and family. One of these participants said that her family explicitly told her that they did not “*want to hear about your dementia all the time*” (P3). This suggests that Twitter might be a safe space for some people with dementia, potentially free from some of the stigma and stereotypes that exist in offline relationships.

Tweeting openly about their experiences of dementia resulted in some participants receiving negative comments from other account holders. Five participants (P2-P5; P11), for example, said they had been trolled or received abusive tweets. One participant (P2) was called a “*lunatic*”, “*mad*”, and “*demented*” by a troll, which was an upsetting experience for him. A different participant was told by another account holder to “*curb what you say to people about your dementia*” (P3), highlighting the risk that other account holders on Twitter might try to silence people with dementia, thereby reinforcing existing offline stigma and stereotypes. While Twitter appears to facilitate self-expression for some people with dementia, this group of people could be vulnerable to abusive comments and trolling.

Four participants (P2; P3; P5; P6) reported that their symptoms hindered self-expression when they made spelling errors in their tweets. These participants often re-read their tweets before posting them, which was an effortful process requiring considerable concentration. It is likely that if tweeting becomes too much effort for

people with dementia, they will stop using Twitter. When asked about how they would feel if they were unable to use Twitter some participants said that they would feel “lonely” or “disconnected” (P1; P5). While it might be a relief for some people to stop using Twitter, it could potentially affect their social connectedness.

P3: *It's a shame that on Twitter you haven't got the edit button because I sent a tweet this morning, the other day, and it was all gobbledegook because my brain wasn't working very well and I think 'oh' so I'll have to delete the whole whereas on Facebook you can edit can't you*

### **5.3..2.3 Using Twitter as a diary**

Five participants (P2; P3; P5; P9; P11) said they used Twitter to document their achievements and experiences so they could look back at them in the future. Four of these participants (P3; P5; P9; P11) discussed wanting to record their experiences because of memory difficulties. In line with this, two of the participants (P2; P5) who used Twitter as a diary had the lowest scores on the MMSE. This finding suggests that tweets could be used by people with dementia to evoke memories, particularly for people with more extensive cognitive impairment or who are experiencing difficulties with memory. One participant (P5) suggested that Twitter, like Facebook, should have a memories option so they could review what they did last month, week, or year.

P5: *It's nice to look back and review your last month or last week on Twitter, or even your last year. So it would be nice... if you want it you can have it, you know, in your settings, to have like a memories option where it can just show you a brief summary of that last year...that would be very nice because obviously the way of dementia, you forget*

One participant (P11) said he had previously recorded his experiences in a diary, but when writing became difficult for him he started to video-record his experiences and tweet about them so he could look back at them in the future. This indicates that some people with dementia who are using Twitter are also using a variety of other platforms to document their experiences, overcome the challenges presented by their symptoms, and facilitate reminiscence in the future.

P11: *They are sort of, they are my substitute for writing really and the channel, the YouTube channel was setup by [name], my daughter, as a library for me really. But then, I think there's nearly 700 subscribers. We never had any intention that people would watch them. It was for my own personal use*

#### **5.3..2.4 Using Twitter as a soapbox**

All participants used Twitter for advocacy, complementing and extending their offline advocacy work. Advocacy work on Twitter included challenging stigma and assumptions about the abilities of people with dementia, campaigning for societal change at a local or policy level, and raising awareness of dementia.

The majority of participants ( $n=10$ ; see Table 5.3) used Twitter to challenge dementia stereotypes and normalise dementia by publicly tweeting about life after a diagnosis and demonstrating their ability to use social media. By tweeting positively about life after a diagnosis of dementia, these participants were using Twitter as a vehicle for societal change to challenge what it means to be a person with dementia. In addition, the participants who used Twitter to normalise dementia wanted to give hope to people who had recently been diagnosed.

P5: *I think if people don't talk about it, discuss it, come out that they have dementia, then we're just perpetuating the very stigma that we complain about. So, the more people that come out, as it were, the more we'll normalise it, and so that's what I set about doing*

By challenging stereotypes on Twitter, campaigning, and presenting themselves as people living with dementia, some participants ( $n=5$ ; P2; P4; P5; P6; P8) received a backlash from other account holders who accused them of not being representative of people with dementia. These tweets were often sent by certain healthcare professionals, carers and family members of people in the later stages of dementia. One participant (P6) and the researcher who conducted the interviews (CT) co-constructed the term “*dementia doubters*” to refer to these groups of people. Having their diagnoses publicly challenged by dementia doubters was frustrating for participants and negatively affected their sense of identity. One participant, for example, said that it made him feel like a “*fraud*” (P6). This finding suggests that while the use of Twitter by participants was generally positive, people with dementia might face negative reactions from other account holders which, in turn, could negatively impact how they see themselves.

As well as challenging dementia stereotypes, eight participants (see Table 5.3) used Twitter to campaign about a diverse range of topics, including rights-based care, post-diagnostic support, palliative care, caring strategies, hospital treatment, and support for people with young-onset dementia. Five participants (P5; P6; P8; P10; P11) reported seeing changes as a result of their campaigns. One participant (P11), for example, said there was a gap in the Alzheimer's Society's services for people with young-onset dementia, but after tweeting about this issue they saw the organisation improve its focus on younger people with dementia. In addition, using Twitter allowed people with dementia to reach a wider audience and connect with

politicians, clinicians, researchers, organisations, local NHS trusts, and local police forces. Through their use of Twitter, these participants were able to alert the people who made decisions that affected people with dementia to their needs, thus potentially facilitating social change.

Participants (P1; P6) said that they used Twitter more for advocacy, whereas they reported using other platforms such as Facebook predominantly for support. This highlights the uniquely political nature of Twitter and its potential to facilitate advocacy compared with other social media platforms. In addition, five participants (P1; P2; P8; P9; P11) did not tweet about the everyday aspects of their lives. Instead, these participants focused on using Twitter as a campaigning tool to “*make a difference to people’s lives and their families’ lives*” (P2). This indicates that the advocates in this study were focused on using Twitter to improve the lives of those affected by dementia.

P6: *Facebook’s more for support.*

I: *Oh okay. And why is that?*

P6: *Because I have a support group so, you know, you’ve got like-minded people. Twitter’s more campaigning and raising awareness. That sort of thing.*

While all of the participants in this study used Twitter as a means to facilitate social change, three participants (P1; P6; P7) said that some politicians and organisations did not respond to their tweets and they saw no societal changes from their campaigning on Twitter. This left these participants feeling discouraged, frustrated, and ignored. Twitter might provide people with dementia with a soapbox through which they can broadcast their perspectives; however, it does not necessarily mean anyone is listening. This finding indicates that while Twitter might

provide a pathway for people with dementia to engage in advocacy, online advocacy by itself might not necessarily be enough to facilitate societal change.

#### **5.3..2.5 Using Twitter as a springboard**

All participants said that using Twitter gave them access to information, which provided new offline opportunities and increased their number of offline social connections. This included attending Dementia Engagement and Empowerment Project (DEEP) group meetings, attending and speaking at conferences, going to dementia cafés, writing book prefaces, speaking on the radio, getting involved in research, and being on advisory boards. Two participants reported that being active on Twitter opened up a “*new world*” (P6; P10) and another participant (P7) said he would never have known about this information if he did not use Twitter. This indicates that these participants used Twitter to extend their offline social worlds and highlights the blurring of boundaries between online and offline spheres where online behaviour can influence offline experiences and vice versa. In addition, three participants (P1; P6; P7) reported becoming initially involved in offline advocacy work because of Twitter. Twitter therefore seems to provide some people with dementia with a pathway to engaging in offline advocacy work and becoming an advocate.

P1: *Then having found some of those people and starting to receive links to documents and meetings and things. I then, that, that lead to my first real involvement with other activists which was a dementia meetup*

#### **5.3..2.6 Using Twitter to enhance self-worth**

Seven participants (see Table 5.3) used Twitter to increase their feelings of self-worth. Three of these participants (P3; P5; P11) discussed using Twitter to feel valued following an initial loss of identity in the aftermath of their diagnosis. These

participants said that they were no longer seen as a parent by their children, had to retire from work, and experienced a loss of abilities such as being able to ride a motorcycle or sign their names. The loss of identity that these participants experienced negatively affected their sense of self and feelings of self-worth. These participants enhanced their feelings of self-worth by using Twitter to help others, educate people about dementia, fight for societal change, and get involved in offline advocacy work. Two participants referred to using Twitter as a “job” (P2; P5), and one of these participants (P2) said that the weekly dementia hashtag chats gave him something to look forward to. This finding suggests that after the loss of identity and purpose that often follows a diagnosis (e.g. Roach & Drummond, 2014), participants used Twitter to facilitate a more positive sense of self-worth.

P5: *I'm not a motorcyclist anymore, I'm not a do-it-yourself-er anymore, I'm far less a husband and father than I was, so this is concentrating on something I can do and that's talking about dementia, and knowing about dementia. So, it's about giving yourself confidence, value, and a sense of purpose*

Four participants (P4; P7; P8; P9) did not say that they used Twitter to enhance self-worth. There were no patterns in the MMSE and IADL scores of participants who did not use Twitter to improve their feelings of self-worth, but it became evident from discussions with three of these participants that they did not use Twitter as frequently as others. This finding was mirrored in the relatively low number of tweets posted by these participants. This lack of engagement with Twitter compared with the rest of the sample could be one reason why these participants did not experience increased feelings of self-worth from using Twitter. While Twitter might be a useful tool to reinstate a sense of purpose and value in some people with dementia, these might only be achieved with regular, intense use.





## 5.4 Discussion

Previous research has shown that people with dementia are using Twitter for advocacy, support, and documenting the lived experience of dementia (Cheng et al. 2018; Talbot et al. 2018,2020; Thomas, 2017). This was the first research study of Twitter to directly engage with the perspectives of people with young-onset dementia and therefore makes a novel contribution to the field. The findings of this analysis clearly demonstrate that people with young-onset dementia are using Twitter for social connection, self-expression, reminiscence, advocacy, accessing information about offline opportunities, and maintaining a sense of purpose.

People with dementia can experience a loss of social contacts and feelings of isolation after receiving the diagnosis (Spreadbury & Kipps, 2019; Griffin, Oyeboode, & Allen, 2016). The findings of this analysis, however, suggest that Twitter could be a valuable tool for people with young-onset dementia to make social connections and combat feelings of isolation. Researchers have emphasised the importance of meaningful relationships for people with dementia (Kitwood, 1997; Sabat, 2006), but have tended to focus on the relationship between people with dementia and their carers, friends, or family members. In contrast, the findings of this analysis highlight the value of relationships between the person with dementia and others with the diagnosis, which can be established and maintained through Twitter. These findings align with recent policy initiatives in the UK, which aim to improve the social connectedness of people who feel isolated (Department for Digital, Culture, Media, and Sport, 2018). In the future, people with dementia could be encouraged to engage with the community of people with dementia on Twitter to help them cope with the diagnosis.

Previous research has shown that people with young-onset dementia can experience a loss of purposeful activity as a result of being unable to work or take part in certain activities (Roach & Drummond, 2014), which is mirrored in the findings of this analysis. The participants in this research, however, used Twitter to maintain their feelings of self-worth by supporting others with the diagnosis, educating people about lived experience, and campaigning for social change. Advocacy can be beneficial for people with dementia as it provides them with a new working identity, anchors them in the present, and allows them to regain respect for themselves and from other people (Bartlett, 2014a; 2014b). Twitter appears to be providing some people with young-onset dementia a pathway to advocacy which, in turn, fosters a sense of purpose and a positive sense of identity.

The use of Twitter by people with dementia to influence social change is consistent with the use of Twitter by other groups of people who have used the platform to raise awareness of societal issues and influence policymaking (Highfield, 2016; Granger, 2013). Online advocacy work has previously been criticised as 'slacktivism', referring to low-impact online action that involves little effort or commitment (Schuman & Klein, 2015). In the context of dementia, however, Twitter seems to be providing some people with dementia a meaningful pathway to advocacy that compliments their offline advocacy work and facilitates social change.

While the findings of this analysis suggest that Twitter is providing some people with dementia access to the organisations and individuals who make decisions that affect their lives, these organisations and individuals may not necessarily take note of the tweets of people with dementia. There has been a recent emphasis on the development of offline communities that are dementia-friendly (Alzheimer's Society, 2013), but this needs to be extended to online communities. Organisations,

researchers, politicians, and other account holders could be encouraged to engage with the tweets of people with dementia to access their perspectives and ensure that online communities are also dementia-friendly and inclusive.

One surprising finding of this study was that some people with dementia used Twitter to record their experiences and achievements so they could use them for reminiscence in the future. In the future, social media posts could be integrated into reminiscence therapy, which has been shown to have positive short-term effects on cognition, quality of life, communication, and mood (O'Philbin, Woods, Farrell, Spector, & Orrell, 2018). This would also provide people with dementia an increased sense of autonomy as they would have control over which experiences are recorded and used for reminiscence.

While it was not the focus of this study, participants reported using different types of social media for different reasons. They used Twitter predominantly for campaigning and raising awareness, Facebook for social connection, and blogging for communicating their perspectives in more detail. This is consistent with previous research on the use of Facebook and blogs by people with dementia (Craig & Strivens, 2016; Kannaley et al. 2019). Although it was beyond the scope of this analysis, future research could directly compare the use of different social networking sites by people with dementia to further explore these distinctions and identify the potential benefits and challenges of using each platform. The findings of this analysis also show that one person with dementia had a YouTube channel which he used to 'vlog' (i.e. video blog) about his experiences of living with the diagnosis. The use of YouTube to communicate experiences of dementia has not yet been examined by researchers. In the future, researchers could use visual and qualitative methods to examine the vlogs of people with dementia.

In this study, the short-text nature of tweets facilitated communication for some people with young-onset dementia. This mirrors the findings of research on the use of Twitter by people with communication disabilities who have benefitted from using Twitter because of limitations in speech (Hemsley & Murray, 2015). Like people with communication disabilities, people with dementia also used Twitter to become visible and communicate their experiences (Hemsley et al. 2015). Twitter appears to provide another medium through which people with young-onset dementia can publicly communicate their perspectives, challenge stereotypes, and reaffirm their diagnosis as a manageable disability. This contrasts with an earlier underrepresentation of the voices of people with dementia in research, whereby it was assumed that they experienced a loss of identity, abilities, and meaningful experiences (Davis, 2004; Moore & Hollett, 2003; Sabat et al. 2011). By facilitating communication, Twitter could be a valuable tool to promote the social inclusion of people with dementia, allowing this group of people to exercise their right to a voice on issues that affect them.

While Twitter could be used to promote the social inclusion of people with dementia, changes may need to be made to the platform itself to make it more accessible. Some of the participants in this study, for example, found it difficult to use Twitter because of their symptoms. Developers have started to recognise that they have a social responsibility to create technology that is ethical and inclusive. Unicode Consortium, for example, recently announced that emoji's with disabilities will soon be made available (Coldeway, 2019). The number of social media users with a diagnosis of dementia is likely to increase as younger people who are more engaged with social media age. It is therefore important that the developers of social networking sites work with people with dementia, as well as other groups of people

with cognitive disabilities, to modify the platform to ensure it is inclusive of, and accessible for, people with cognitive disabilities.

Research on the use of Twitter by people with dementia has tended to focus on positive uses of the platform (Talbot et al. 2018, 2020). While the use of Twitter by people with dementia in this research was mainly positive, some participants received negative tweets from other account holders. For other groups of people, research has shown that trolling negatively impacts mental health and wellbeing (e.g. O'Reilly et al. 2018). This is also likely to be true for people with dementia who may be particularly vulnerable to trolling because of the stereotypes associated with dementia. Some participants in this research also received tweets from certain healthcare professionals challenging their diagnoses, which reflects recent debates about the diagnoses of some dementia advocates (e.g. Howard, 2017). While it is true that people can be misdiagnosed with dementia, exposure to these comments on Twitter may cause people who do have dementia to unnecessarily question their diagnostic identity which, in turn, could negatively affect their wellbeing and sense of self.

#### **5.4.1 Limitations**

Although we did not set out to recruit only people with young-onset dementia, all of the people who participated in this study had young-onset dementia. It has been estimated that only 5% of people with dementia are diagnosed before the age of 65 (Prince et al. 2014). The sample included in this study are not, therefore, representative of the majority of people with dementia. The findings of previous research, however, suggest that the population of Twitter users with dementia is small and comparatively young (Talbot et al. 2018), so the current sample does

appear to be representative of Twitter users with dementia. In addition, it is likely that the population of Twitter users with a diagnosis of dementia will increase in size as younger generations who are more engaged with social media age (Smith & Anderson, 2018). It is therefore valuable to understand how people with dementia are using Twitter, the perceived benefits of using the platform, and the challenges they face. This study also provides an important foundation for future research on the social media needs and experiences of those diagnosed with dementia later in life.

The sample also lacked diversity as participants were all white British, reasonably young, and tended to have reasonably high socioeconomic status. A lack of diversity meant that other aspects of social difference, such as ethnicity and socio-economic status could not be explored in this study. It is likely that other groups of people with dementia, such as those who identify as ethnic, gender, or sexual minorities and so face additional stigma (e.g. Adelman, 2016; Barrett, Crameri, Lambourne, Latham, & Whyte, 2015), may have different experiences of using Twitter. These groups of people with dementia might, for example, use Twitter to advocate about issues that directly affect them and connect with people with whom they share experiences. It is also possible that these groups of people with dementia face specific challenges when using Twitter, such as discrimination, targeted trolling, and issues of inclusivity. In the future, researchers could adopt an intersectional approach and recruit more diverse samples to examine the experiences of different groups of people with dementia who use Twitter.

All participants in this study had previously engaged in offline advocacy work, so it is difficult to determine whether the findings can be applied to people with dementia who do not identify as advocates. Although we did not specifically aim to recruit

advocates, it was only advocates who expressed an interest in taking part in this research. This could indicate that advocates are more likely to use Twitter and are more likely to report a diagnosis of dementia in their profile. Future research could be conducted with non-advocates to determine whether they use Twitter differently; however, these people might be difficult to recruit.

In this analysis, the researchers did not have access to data on participants' Twitter usage pre-diagnosis. Consequently, it is difficult to determine how the use of Twitter by participants changed after receiving a diagnosis. In the future, researchers could analyse the tweets of people with dementia before and after diagnosis to examine whether and how their use of Twitter changes after receiving a diagnosis of dementia.

The focus of this analysis was cross-sectional rather than longitudinal. An  $n=1$  study of terminal cancer found that the person used Twitter for different reasons during different stages of the disease trajectory (Taylor & Pagliari, 2018). This could also be true for people with dementia. For example, people with dementia might use Twitter more for advocacy in the early stages and more for peer support in the later stages. A longitudinal analysis of these data is reported in the next chapter (see Chapter 6).



## **5.5 Conclusion**

In conclusion, the findings of this research suggest that people with young-onset dementia are using Twitter for advocacy, social connection, self-expression, recording and looking back at experiences, accessing information about offline opportunities, and enhancing self-worth. People with dementia who are interested in using Twitter could be encouraged to use the platform to cope with the diagnosis, communicate, and get involved in advocacy work if these are of interest; however, there are some risks involved as people with dementia might receive abusive comments online and face technical difficulties when using the platform. In the future, researchers could examine how the use of Twitter by people with dementia changes as symptoms progress to understand the challenges they face when using the platform. This information could then be used by platform developers to make Twitter more accessible for and inclusive of people with dementia.

**Chapter 6**

**Changes in the use of Twitter by People with Young-onset Dementia: A  
Longitudinal Analysis**

## **6.1 Rationale and Research Aims**

Recently, researchers have suggested that Twitter could be a valuable tool for people with dementia to facilitate advocacy, social-connection, self-expression, reminiscence, an increased sense of self-worth, and to increase the size of offline social networks (see Chapter 5; Cheng et al. 2018; Talbot et al. 2018, 2020; Thomas, 2017). While the findings of research on the use of Twitter by people with dementia are largely positive, it is likely that people with dementia will find it more challenging to use Twitter as symptoms progress. People with dementia might also use Twitter for different reasons at different stages of the disease trajectory; for example, people with dementia might use Twitter as a source of support as symptoms progress rather than focusing on advocacy. Longitudinal research examining the challenges that people with dementia face when using Twitter is important because it is likely that the number of users with a diagnosis of dementia will increase as younger generations, who are more engaged with social media, age (Smith & Anderson, 2018). In addition, just as there is a growing recognition that offline spaces should be dementia-friendly (Alzheimer's Society, 2013), it is also important that online spaces are accessible for and inclusive of people with dementia. This led us to our research aim, which was to examine how the use of Twitter by people with dementia changes over time.

## **6.2 Method**

### **6.2.1 Design**

This study built on three previous studies which examined the use of Twitter by people with dementia (Talbot et al. 2018, 2020; see Chapter 5). This study had a longitudinal multiple case-study design, in which a single case was an individual with dementia. This study took place over a period of one year. Data were collected at three timepoints: entry to the study (baseline); six months; and 12 months. Measures of cognition and functional ability, a series of in-depth interviews, and tweet frequency were also included in the design. These measures were used to examine how the effects of dementia on cognition and functional ability affected participants' use of Twitter. This study was approved by the Human Research Ethics Committee of the University of Exeter Medical School.

## **6.2.2 Measures**

### ***6.2.2.1 Mini-Mental State Examination***

The Mini Mental State Examination (MMSE; Folstein et al. 1975) was used to measure cognitive functioning at each timepoint. The MMSE is a brief cognitive assessment that assesses cognition across seven domains: orientation to time; orientation to place; registration; attention and calculation; recall; language; and visual construction. The test takes 5–10 minutes to administer and total test scores range from 0–30, with lower scores indicating greater impairment.

### ***6.2.2.2 Instrumental Activities of Daily Living***

The self-rated version of the Lawton and Brody Instrumental Activities of Daily Living (IADL; 1988) was used to measure functional ability at each timepoint (See Appendix I). The self-rated version of the IADL scale assesses functioning across nine dimensions: preparing own meals; using the telephone; shopping for groceries;

getting to places out of walking distance; doing housework; doing handyman work; washing clothes; managing money; taking medications. Each activity is reported as being done without help, with some help, or not at all. A trichotomous version of this scale was used (1 = unable; 2 = able with help; 3 = able without help) with a possible total score between 9 and 27, with lower scores indicating greater dependence.

#### **6.2.2.3 *Tweet frequency***

Tweet frequency was examined using Twitter Analytics, which is a free service provided by Twitter that allows users to examine their social media analytics. Monthly tweet frequency was used to identify increases or decreases in the number of tweets sent by participants. Frequency of retweets were not included in this measure because Twitter Analytics does not collect this data.

#### **6.2.2.4 *Interviews***

A series of semi-structured interviews were conducted with participants to examine changes in their experiences of using Twitter. Interviews were conducted with participants on entry to the study, and follow-up interviews were conducted six- and 12-months after the initial interview. The initial interviews were used as baseline measures of how and why participants use Twitter, and follow-up interviews were conducted to identify any changes in their use of Twitter.

Interviews with participants were split into two sections. In the first section, participants were asked about their use of Twitter, which was guided by the interview schedule (see Appendix J-L). Interview schedules were developed by the research team, and reviewed by a group of people with dementia who used Twitter and acted as advisors on the study. The first interview schedule focused on reasons for joining Twitter, reasons for using Twitter, self-presentation and expression, interactions, and barriers. The interview schedules for follow-up interviews focused on changes in dementia and use of Twitter, but also included additional questions and clarifying questions which arose from the initial interviews (see Appendix J-L).

The second part of the interview followed an adapted version of the scroll back method (Robards & Lincoln, 2017). The scroll back method involves participants

scrolling through their social media posts and discussing them with a researcher as part of a semi-structured interview. In this study, an adapted version of the scroll back method was used whereby participants were presented with a random sample of 10 tweets (including retweets) that they had posted in the previous six months. The scroll back method was included at each timepoint. For each tweet and retweet, participants were also asked to explain why they sent the tweet, what they aimed to achieve by posting the tweets, and how they felt at the time they composed the tweet. Ahead of each interview, the first author also examined the sample of tweets and identified any changes in the type of content posted by participants between timepoints. Participants were also asked about any changes that were observed by the researcher.

### **6.2.3 Recruitment**

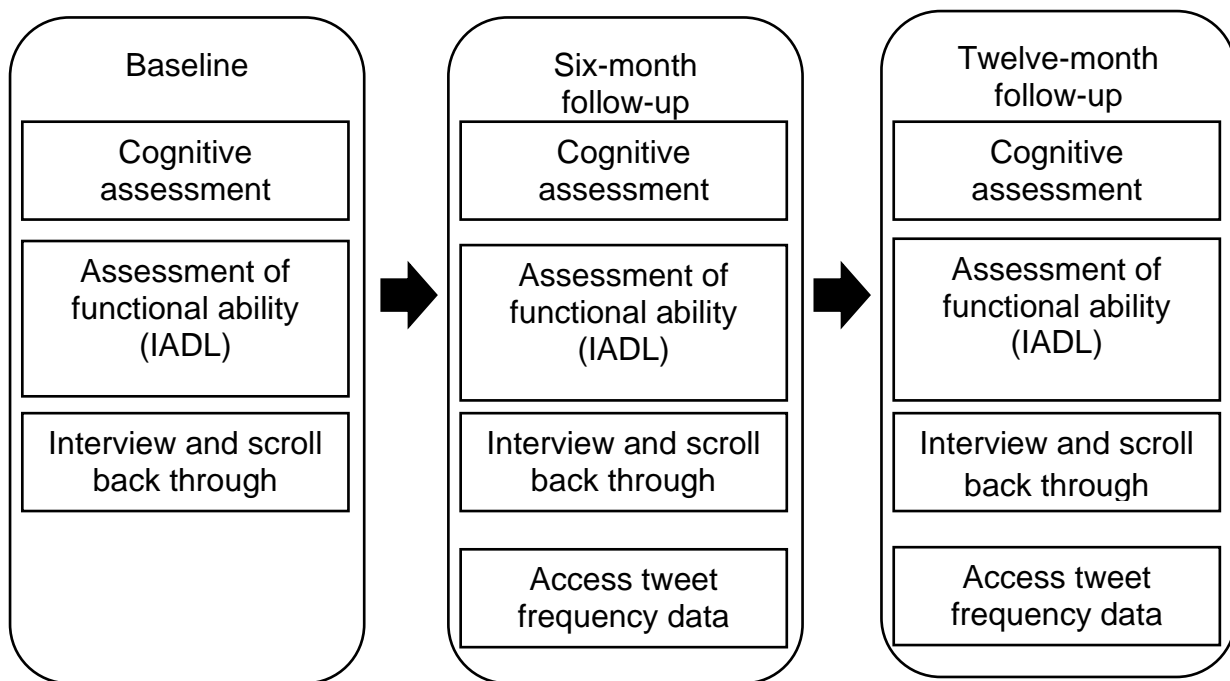
Participants were sampled from a population of Twitter users identified in a previous study (Talbot et al. 2018). For practical reasons, the sample was limited to account holders located in the UK. The first author tweeted 14 UK account holders with a self-reported diagnosis of dementia informing them of the research. Five account holders consented to take part in the study.

To increase the size of the sample, Twitter was searched for UK account holders who identified themselves as having dementia and were not located in the previous study (see Chapter 5). Existing participants and advisors on the study were also asked if they knew of anyone who might be interested in taking part in the research. A further six people with dementia consented to take part in the study, resulting in a sample of 11 participants. One participant dropped out of the study after the first interview due to ill health, resulting in a final sample of 10 participants.

#### **6.2.4 Procedure**

Participants completed the self-rated version of the IADL scale before interviews. Following this, the first author (CT) met participants at their homes or a place of their choosing. Before the interviews took place, CT administered the MMSE to participants. All participants completed the serial sevens calculations task at each timepoint and therefore did not complete the task where they are asked to spell “world” forwards and backwards. After completing the MMSE, interviews were conducted with participants, which included the scroll back method. All interviews were conducted in person by the CT. Interviews were recorded using a digital device and ranged in length from 35–80 minutes. This process was repeated six- and 12-months after the initial interview. After interviews at six- and 12-month follow-up, the first author accessed participants’ Twitter Analytics data to record monthly tweet frequency. The research process is illustrated in Figure 6.1.





*Figure 6.1.* Research process. Data collected on entry to the study and at six- and 12-month follow-up.

After each timepoint, interviews were transcribed verbatim and anonymised. Intelligent verbatim transcription was used to remove fillers and repetitions when the speech of participants was particularly broken, which detracted from the content of the data. In the transcripts, and the data presented in this paper, “I” refers to the interviewer and “P(ID)” refers to participants. Identifiable data about places and names of people who were not included in the sample were also removed from the transcripts and replaced with “[substitute term]”.

### 6.2.5 Analysis

MMSE scores, IADL scores, and tweet frequency per month were tabulated and analysed descriptively to examine changes in cognition, functional ability, and the number of tweets posted per month.

A recurrent cross-sectional analysis was conducted to analyse interview data, whereby themes and changes over time were examined across the sample (Grossoehme & Lipstein, 2016). CT began by familiarising herself with the data by reading the anonymised transcripts and making notes of initial ideas for coding. The second author (SoD) also familiarised herself with the data by listening to audio recordings of the interviews, and the third (LC) and fourth (JH) authors read two anonymised transcripts from the same two participants at each timepoint. Following this, CT generated initial codes and the co-authors made coding suggestions. CT coded all of the anonymised transcripts using QSR International's NVivo 11 software. Interview data from each timepoint were coded separately. Transcripts from the initial interviews were coded to provide baseline measures of how and why participants used Twitter. The coding of transcripts from six- and 12-month follow-up interviews focused on changes in participants' use of Twitter and changes in symptoms of dementia that affected their ability to use Twitter.

After all interviews were coded, CT organised the data into a series of time-ordered matrices (Miles & Huberman, 1994). A matrix was created for each participant with time on the x axis and codes on the y axis (see Appendix O for an example). The cells in these matrices contained data summaries and direct extracts from interview transcripts. Following this, CT manually coded the matrices to identify patterns of change across participants. Codes were then reviewed by CT and initial longitudinal themes were generated. The longitudinal themes were reviewed by the

rest of the research team, and changes were made to themes where appropriate. CT then created a longitudinal matrix with longitudinal themes across the x-axis, participant ID across the y-axis, and data summaries in the cells to visualise the data (see Appendix P for an example). Subsequently, CT examined the longitudinal themes in relation to changes in MMSE scores, IADL scores, and tweet frequency.

## **6.3 Results**

### **6.3.1 Participants**

Ten people with young-onset dementia participated in the study, comprising seven men and three women. All participants were white British. Most participants had managerial or professional occupations before retirement. Five participants provided information about their level of education. Four of these participants had a university degree, one participant had a Level 4 National Vocational Qualification (NVQ), and one participant had college-level qualifications. Participants had an average age of 59.8 years (range = 48–66) and the average age at diagnosis was 54.5 years (range = 45–63). Participants had been living with a diagnosis of dementia for an average of 5.3 years (range = 1–9). Most participants had mixed dementia ( $n=4$ ), followed by Alzheimer's disease ( $n=2$ ) and vascular dementia ( $n=2$ ), and posterior cortical atrophy ( $n=1$ ). One participant was unsure of her diagnosis. All participants had engaged in offline dementia advocacy work before taking part in this study, such as lobbying politicians, speaking at conferences, and educating students about lived experience.

Participants had used their Twitter accounts for an average of 4.6 years ( $SD = 2.32$ ; range = 2–8 years), had an average of 2,882 followers ( $SD = 3,936$ ; range =

79–12,100), followed an average of 2,172 account holders ( $SD = 3866$ ; range = 68–12,337), and had posted an average of 15,195 tweets since joining Twitter ( $SD = 23,800$ ; range = 1280–65,000). Table 6.1 contains descriptive details of the participants and their Twitter profiles.

Table 6.1. *Descriptive details of the participants and their Twitter profiles.*

ID	Sex	Age	Age diagnosed	Ethnicity	Previous occupation	Highest level of education	Type of Dementia	Followers	Following	Total tweets posted	Joined Twitter
1*	M	66	63	White	School business manager	University degree	Mixed	2184	1,050	8,190	2011
2*	M	65	57	White	Senior manager	NVQ (Level 4)	Alzheimer's	7681	5,016	54,403	2013
3	W	48	45	White	Nurse	University degree	Posterior Cortical Atrophy	2904	1,350	42,600	2017
4	M	65	56	White	Police officer	-	Vascular	776	169	5,523	2014
5	M	57	51	White	Property manager	College education	Mixed	12,113	12,337	65,382	2013
6	M	55	54	White	Clinical support worker	University degree	Mixed	1,180	1,084	8,966	2011
7	W	59	53	White	Business support manager	University degree	Unknown	442	149	214	2016
8	M	66	57	White	Lorry driver	-	Vascular	79	68	128	2016
9	W	64	59	White	Horticulturist	-	Mixed	1,094	384	5,952	2016
10	M	53	50	White	Business owner	-	Alzheimer's	366	113	674	2017

\*Also participated in Study Two

### 6.3.2 Cognition and functional ability

Participants' scores on the MMSE ranged from 14 to 30 at initial assessment, which is consistent with mild to moderate dementia (Folstein et al. 2001). There were no instances of substantial decline in MMSE scores. Participants' IADL scores ranged from 11 to 28 and were relatively stable over time. While there were no instances of substantial decline in MMSE and IADL scores, the range in scores between participants suggests that they were at different stages of the disease trajectory. The MMSE and IADL scores for participants at each timepoint are reported in Table 6.2.

Table 6.2. *Participant scores on the Mini Mental State Examination and the Independent Activities of Daily Living scale.*

ID	MMSE T1	MMSE T2	MMSE T3	IADL T1	IADL T2	IADL T3
P1	29	30	28	23	23	22
P2	16	21	23	12	13	14
P3	28	27	29	26	26	26
P4	19	22	20	12	10	11
P5	14	18	21	13	13	12
P6	24	25	26	21	18	19
P7	29	30	30	27	26	25
P8	24	24	29	20	22	22
P9	17	21	22	21	21	21
P10	20	18	19	16	15	17

### **6.3.3 Tweet frequency**

The number of tweets posted by participants each month ranged from zero to 561 (see Table 6.3). Data are missing for month seven to ten because of changes that were made to Twitter Analytics' application programming interface (API) during the study, which limited the amount of data that could be accessed. Twitter Analytics data were also not collected for one participant (P4) at six-month follow-up because of internet access issues and data were not collected for another participant (P5) because he was unable to log into his Twitter account. The tweet frequency for month 11 is irregular when compared to the rest of the data, which might be because of changes to Twitter's API.

Before the six-month follow-up, however, there were substantial decreases in tweet frequency by four participants (P1, P3, P5, P6). At month 5 (August), P3 decided to take a break from Twitter which is reflected in a decrease in tweet frequency at this time. In general, tweet frequency tended to increase at month six, which could be because participants were aware that they would soon be visited for the six-month follow-up interview. The tweet frequency scores also show that at 12-month follow-up, one participant (P10) had stopped tweeting altogether.

Table 6.3. *Frequency of tweets posted by participants each month*

ID	Month											
	1	2	3	4	5	6	7	8	9	10	11	12
1	29	64	46	48	33	104	-	-	-	-	3	75
2	561	298	261	137	310	286	-	-	-	-	3	394
3	386	785	281	116	21	85	-	-	-	-	13	330
4	-	-	-	-	-	-	-	-	-	-	4	11
5	73	57	18	19	14	38	-	-	-	-	-	-
6	282	323	286	354	195	128	-	-	-	-	6	248
7	3	1	0	2	28	3	-	-	-	-	2	20
8	4	1	13	1	1	3	-	-	-	-	1	6
9	87	76	76	76	87	132	-	-	-	-	3	165
10	17	18	18	12	13	22	-	-	-	-	0	0

#### 6.3.4 Longitudinal qualitative analysis

Three themes were generated through the analysis: using Twitter becomes more demanding; using Twitter less for social purposes; using Twitter more for advocacy. These themes are discussed below with representative anonymised quotes from interviews to illustrate each theme. The representation of each theme across participants is reported in Table 6.4.

Table 6.4 *Representation of themes across participants.*

Theme	Month									
	1	2	3	4	5	6	7	8	9	10
More demanding			X	X	X	X	X	X		X
Less for social purposes	X				X					
More for advocacy	X	X			X	X				



#### **6.3.4.1 Using Twitter becomes more demanding**

Seven participants (see Table 6.4) said they experienced increased difficulties with their symptoms of dementia at six- and 12-month follow-up that impeded their ability to use Twitter. These included increased difficulties with concentration, memory, word-finding, spelling, and typing. This finding, however, was not reflected in the MMSE data.

Participants who said they experienced increased problems with concentration at six-month and 12-month follow-up ( $n=5$ ; P4, P5, P6, P8, P10) also said that using Twitter had become more cognitively demanding, which made it tiring for them. This was reflected in a decrease in tweet frequency by two of these participants (P5, P10) before the six- and 12-month follow-up, respectively. While one participant (P5) reported increased difficulties with concentration at six-month and 12-month follow-up, it was not reflected in his MMSE score which increased substantially after the initial interview. This could be because the participant reported feeling tired at the initial interview, which might have resulted in a lower MMSE score.

At six-month follow-up, one participant (P10) commented that he found the pace of Twitter difficult to manage, so he started using Facebook more than Twitter, but by the 12-month follow-up interview he was hardly using any social media because it had become “*hard work*”. This participant also had the lowest MMSE score at six- and 12-month follow-up, and his IADL scores were below average for the sample, which might explain why he experienced difficulties using the platform.

P10:        *It's a job to read everything. Twitter or Facebook. Facebook is a little slower than Twitter. Twitter is quite fast and boom boom boom. It's*

*there, it's there and it's all in the moment. And yeah, I suppose if there's more than a few lines to read I just can't even do it so I don't even do it.*

At six-month follow-up, two participants (P3, P5) said they took more breaks from using Twitter to deal with the cognitive demands of the platform. This was reflected in a decrease in the number of tweets one participant (P3) sent in August (month 5), which was when she took a break from using Twitter. While breaks were necessary for both of these participants (P5, P3) so they could feel rested and therefore able to return to using Twitter in the future, one of these participants (P5) said he often felt isolated when he was not able to use Twitter.

I: *How does it feel when you're not able to use Twitter?*

P5: *Erm. Then you do feel a bit isolated. You do feel a bit lonely. But needs must. You know, you're just tired and you've just got to do it. You've got to have a break.*

In line with this participant's (P5) comment that he felt isolated when he was unable to use Twitter, another participant (P10) said he had lost touch with a lot of friends because he stopped using Twitter. Although this was an upsetting experience for this participant (P10), he tried not to dwell on the social contacts he had lost because it made him feel "very depressed". Instead, this participant stopped using Twitter and focused on abilities and social activities he retained, such as cycling.

P10: *I'm getting my head around it really and think well if I can't do it, I can't do it. And that's all there is about it. I've got good cycling friends, [name], so I spend a lot of time with her. So, yeah that's all I can do.*

Two participants (P6, P8) experienced increased word-finding difficulties at six- and 12-month follow-up. These participants said they would sometimes tweet words

that they did not mean to use. One participant (P8) said he would often re-read a tweet before posting it to ensure there were not any mistakes, which was an effortful process. At 12-month follow-up, two participants (P3, P6) found typing increasingly difficult. One of these participants (P6) said he was able to type quickly before he had dementia, but at the 12-month follow-up interview, he said he would often mix words together or use the wrong letter when composing tweets. This was a frustrating experience for this participant because he used computers regularly prior to receiving his dementia diagnosis.

I: *Okay, and how does it feel that you're not able to use Twitter as much?*

P6: *Annoying.*

I: *Okay. Could you tell me a bit more about that?*

P6: *Well because I've used computers for 40 years and, you know, when I worked in the [office] I could go faster on the computer and stuff like that and now it's, erm, I know what I want to type but my fingers will type a load of rubbish and I'll have to go back and amend it all and I'll mix words together or just type the wrong letters or whatever, so that's become an issue as well.*

Although the majority of participants ( $n=7$ ) said they found Twitter more challenging to use as they experienced more difficulties, some participants also said they used strategies to overcome the challenges they faced. Three participants (P5, P6, P11), for example, used voice application software to compose tweets. Family members also helped participants (P5, P10) to use Twitter by showing them how to use the platform and in the case of one participant (P5) setting up voice-activated software. In addition, at six- and 12-month follow-up, one participant (P5) said he tended to retweet rather than compose individual tweets as he found it too challenging, which was mirrored in a decrease in the number of tweets sent by this participant before the six-month follow-up interview. This is also consistent with

another participant's (P3) use of Twitter where she would retweet more information, rather than compose her own tweets, on days when she was tired and struggling with word-finding. While the cognitive demands of using Twitter made it difficult for both of these participants (P3, P5) to tweet, retweeting and the use of voice application software was one way that some participants continued to engage with Twitter.

P5: *So now my daughter's set up... activated Siri, which I didn't know about. I've had this on for a while now. On those days, I'll activate Siri as well so while I'm reading, Siri is also reading it to me, and it reinforces it, and I do understand it a lot better.*

#### **6.3.4.2 Using Twitter less for social purposes**

Two participants (P1, P5) said they used Twitter less for social purposes at 12-month follow-up, which contrasts with their responses at the initial interview where they used Twitter to access peer support and connect with other people with dementia. At the initial interview, one participant (P1) said he used Twitter to keep in contact with dementia advocates from around the country who were his "*brothers in arms*", but at six-and 12-month follow-up he said he no longer used Twitter for social reasons. He also commented at 12-month follow-up that he was withdrawing from social contact more generally.

P1: *I'm beginning to I think to withdraw a little bit from social contact around the country, I'd say. I'm beginning I suppose to care less about meeting other people elsewhere...how can I put it? I suppose I'm just not bothered any more. I don't... I can't really pin it down any more than that, I've just lost interest in following what other people are doing.*

These two participants (P1, P5) also stopped using Twitter for peer support at 12-month follow-up because they wanted to focus on using the platform for campaigning, awareness raising, and distributing information. At the 12-month follow-up interview, one of these participants (P5) said he no longer used Twitter for peer support as he did not want to dwell on the progression of his symptoms. Instead, he used Twitter to focus on what he was still able to do (i.e. campaign). For this participant, Twitter was a valuable tool to distract him from self-reported symptom progression, and online advocacy was something positive he could focus on instead.

I: *So are you also using it for peer support still?*

P5: *I wouldn't say so, not so much. No. I've gone not as... less personal*

I: *Ok, and why is that?*

P5: *I don't know. I find that's just easier. It's a coping mechanism, I think. Yeah.*

#### **6.3.4.3 Using Twitter more for advocacy**

Four participants (P1, P2, P5, P6) said they used Twitter more for advocacy at six- and 12-month follow-up. As previously discussed, two of these participants (P1, P5) used Twitter more for advocacy because they were less interested in using the platform for social purposes. This included using Twitter more for campaigning and raising awareness, tweeting more about the rights of people with dementia, and taking part in advocacy-focused hashtag discussions. At six-month follow-up, one participant (P2) said he was using Twitter more for campaigning after becoming involved in offline advocacy and being inspired by the tweets of prominent dementia advocates:

P2: *I think originally I became more aware of the rights and how important they were from people like [name; person with dementia] and others. What they were tweeting and what they were writing about.*

While there were no patterns of change in the IADL and MMSE scores of participants who used Twitter more for advocacy, one participant (P6) said his mood had improved since the initial interview which, in part, he attributed to his use of Twitter. At the initial interview, this participant had been diagnosed with dementia for less than one year and was still adjusting to the diagnosis, which might explain why his mood was low on entry to the study. This participant also scored higher on the MMSE at six- and 12-month follow-up, so it is possible that improvements in mood affected his scores. At six-month follow-up, this participant said that using Twitter provided him with access to information about opportunities that he could get involved with offline and he started engaging in advocacy (both online and offline) which gave him a sense of purpose and, in turn, improved his mood.

P6: *I mean, when I last saw you I was probably still sitting indoors. I wasn't going anywhere. There's the memory cafes by the shops just round the corner, I didn't even know anything about it until a couple of months ago.*

I: *Yeah because you seem a lot better, I think. And do you think that's because you're doing all of the-*

P6: *-It's because I'm achieving something, or hopefully achieving something.*

## **6.4 Discussion**

This study was the first to examine changes in the use of Twitter by people with dementia over time. Examination of standardised measures showed no instances of

substantial decline on measures of cognition and function ability; however, descriptive analysis of tweet patterns revealed that some participants tweeted less frequently and one participant stopped tweeting altogether. The longitudinal qualitative analysis also yielded some insights into the changing forms of Twitter usage. Three themes were generated through the qualitative analysis: using Twitter becomes increasingly demanding; using Twitter less for social purposes; and using Twitter more for advocacy. These findings suggest that the use of Twitter by people with dementia can vary according to the stage of the disease trajectory. While participants' dementia was stable across standardised measures of cognition and functional ability, they nevertheless described challenges to using Twitter over time (e.g. difficulties with typing, struggling to keep up with the pace of Twitter) and this was accompanied by some shift in how they used Twitter (e.g. taking breaks, retweeting rather than composing tweets, using voice-activated software). Twitter might be particularly valuable for people in the earlier stages of dementia, and for people who have recently been diagnosed, as it provides them with access to important information and allows them to get involved in advocacy, but as they subjectively experience symptom progression they tend to use the platform less and eventually leave Twitter.

While there were no instances of substantial decline on standardised measures of cognition and functional ability, participants subjectively reported advancing symptoms that affected their ability to use Twitter. The MMSE and IADL scales are generally considered to be reliable, are widely used to measure changes over time, and are often used as outcome measures in trials (Webster et al. 2017). In this study, however, these measures might not have been sensitive enough to detect changes in symptom progression but these changes were substantial enough to

affect the everyday experiences of participants. It is also possible that there were other contextual factors such as the presence of other health conditions and seasonal factors, which may have influenced participants' use of Twitter but were not the focus of this analysis. In the future, a longer timeframe could be used to examine more substantial changes in symptom progression which might be identified using standardised measures of cognition and functional ability.

Twitter can be beneficial for some people with dementia as it facilitates social connection and provides a pathway to advocacy, which fosters a sense of purpose (see Chapter 5). Previous research has shown that offline advocacy can be beneficial for people with dementia as it provides them with a new working identity (Bartlett, 2014a, 2014b), and the findings of the current research extend this to online advocacy. In particular, using Twitter for advocacy was beneficial for the participants in this study because it distracted them from symptom progression and provided them with something to focus on shortly after receiving a dementia diagnosis. Discussions about dementia have often focused on the loss of abilities and loss of identity (Naue & Kroll, 2008; Davis, 2004). From a citizenship perspective, Twitter appears to be providing some people with dementia a space where they can focus on abilities they have retained and therefore feel they are making a meaningful contribution to society, counteracting the threats to identity posed by symptom progression in the early stages of dementia.

While there appear to be clear benefits of using Twitter for people in the earlier stages of the disease trajectory (see Chapter 5), the findings of this research show that people with dementia find it more challenging to use as they subjectively experience advancing symptoms. While it might be a relief for some people to tweet less, shift from tweeting to retweeting, take breaks from Twitter, or stop using Twitter



altogether, it is possible that some people with dementia might feel less socially connected as a result. In addition, while retweeting might be one way that people with dementia can continue to meaningfully engage with Twitter, it is often unclear what a retweet signifies as it can be used to demonstrate listening, express public agreement, or to save for future reading (Boyd et al. 2010). Consequently, the messages of advocacy that people with dementia are trying to communicate on Twitter might become diluted. Retweets are also not the original words of the person with dementia, whereas illness narratives are usually communicated using the person's own words (Sakalys, 2003; Vanderford et al. 1997). A shift to retweeting information rather than composing individual tweets by people with more advanced symptoms may serve to inadvertently silence individual narratives of those in the later stages of the disease.

If people with dementia find it more difficult to use Twitter as they subjectively experience symptom progression, their social connection with other account holders may also be at risk. It became evident through the interviews in this study that some of the participants knew each other and would sometimes meet up offline at advocacy-related events, highlighting that Twitter use is not an isolated phenomenon but is part of a wider context that includes offline meetings and offline advocacy work. While these participants might lose several social contacts as a result of being unable to use Twitter, they could still have a collective group identity and strong offline support networks as a result of offline group membership. Clare and colleagues (2008) have shown that identifying with a community can be beneficial for people with dementia to develop a shared social identity, foster mutual strength, and increase feelings of self-worth. Unlike the participants in this study, however, other Twitter users with a diagnosis of dementia may not be members of offline groups.

For these people, reductions in, or an end to, their Twitter use could lead to a loss of identity as a result of disconnecting from this community. For other groups of people, researchers have found that people who strongly identified with a group and experienced a threat to their group membership reported reduced self-concept clarity (i.e. the extent to which *self*-beliefs are clearly and confidently defined, internally consistent, and stable) and reduced self-esteem (Slotter et al. 2015). In the future, research could be conducted with people with dementia who have stopped using Twitter to further examine the impact that leaving Twitter has on their social connectedness and sense of identity.

Despite finding Twitter more challenging to use as they subjectively experienced symptom progression, the participants in this study found innovative ways to continue using the platform (e.g. voice-activated software), which demonstrates their enthusiasm for the platform and the importance of it in their lives. By finding technical solutions to overcome the challenges posed by dementia, the participants in this study have also demonstrated that they are technologically skilled. This stands in stark contrast to stereotypical beliefs about people with dementia, which portray them as sufferers who are unable to learn new skills and who experience a loss or erosion of self (Milne, 2010). While stereotypical views of dementia still persist today, recent research has shown that people with mild-to-moderate dementia are able to learn new skills if they are given appropriate support (e.g. Lekeu, Wojtasik, Van der Linden, Salmon, 2002; Clare, Evans, Parkinson, Woods, Linden, 2011). In the GREAT trial (Clare et al. 2019), some people in the early stages of dementia set realistic goals related to learning to use devices, including tablets or iPads, computers, and laptops, and the internet, and were able to achieve these goals with support from a cognitive rehabilitation practitioner. In the future, using social

networking sites such as Twitter could be a functional goal for people with early-stage dementia who are interested in using social media.

There are also several modifications that the platform developers of Twitter could make to facilitate greater access for people with dementia. The platform developers of Twitter could, for example, better integrate voice-activated software or include a spellcheck or edit feature. There is increasing pressure for offline spaces and communities to be dementia-friendly (e.g. Bartlett, 2016; Alzheimer's Society, 2013), but it is also important that online spaces are accessible for people with dementia. In addition, there is a growing recognition that the creators of social media have a social responsibility to develop technology that is ethical and inclusive (e.g. Coldeway, 2019; Schneble, Elger, & Shaw, 2018). The platform developers of Twitter could therefore consider working with people with dementia in the future to reflect on the accessibility of the platform and make modifications that respond to the needs of this group

One participant in this study used Twitter less for social purposes because he had started to withdraw from social interaction more generally, which is a common experience for people with dementia (e.g. Honda, Meguro, Meguro, Akanuma, 2013; Moretti, Torre, Antonello, Cazzato, 2006). This finding is pertinent because it suggests the online behaviour of people with dementia might reflect their offline experiences. For people with other chronic health conditions, such as eating disorders, there is a substantial amount of research that has shown online behaviour is positively associated with measures of symptomology (e.g. Bachner-Melman, Zontag-Oren, Zohan, & Sher, 2018). In the future, researchers could use computational methods to examine tweets and identify potential cases of dementia; however, researchers should take extreme care when applying the findings. This is

well illustrated through the case of the Samaritans Radar application, which detected Twitter users who were experiencing suicidal thoughts and was shut down over claims that it was an invasion of privacy (Samaritans, n.d.).

The findings of this research also indicate that Twitter may not be an appropriate avenue for support for some people with dementia, particularly as symptoms progress. It is possible that the participants in this study did not use Twitter for support because they were self-identified advocates who wanted to challenge dementia stereotypes. Publicly tweeting about the difficulties they experience could further perpetuate the stereotypes dementia advocates are trying to challenge. It is therefore essential that people with more advanced symptoms receive appropriate peer support. This is particularly important for people with young-onset dementia who face distinct challenges in comparison to those diagnosed later in life, as they tend to have more financial commitments, relatively younger children, and still be working at the time of diagnosis (Johannessen & Möller, 2010; Roach & Drummond, 2014). Future research could examine different ways that technology could be used or adapted to provide peer support networks for people with dementia.

Similar to writing books (e.g. Mitchell, 2019) and speaking at conferences (Gilmour & Brannelly, 2010), the findings of previous research suggests that people with dementia have used Twitter to communicate their personal narratives and engage in a social dialogue that promotes social change (Talbot et al. 2020; see Chapter 5). Despite this, the findings of the current study indicate that only the narratives of people in the earlier stages of dementia are represented on Twitter. While Twitter might be a useful platform for researchers, practitioners, and policymakers to engage with the perspectives of people with dementia, it might only provide the perspective of people in the early stages and not represent the needs of

those with more advanced symptoms. Bartlett (2014a) theorised that dementia advocacy might cause a 'status gap' between people who are able to communicate their experiences and those who are not. Twitter might exacerbate this status gap, causing people with more advanced dementia to continue to experience stigma and discrimination. It is therefore important that researchers, practitioners, and policymakers use other avenues to access the perspectives of people with dementia who are not active on social media.

#### **6.4.1 Limitations**

Although this study clearly showed that the use of Twitter by people with dementia changed as they subjectively experienced symptom progression, there were some limitations. Firstly, data collection was limited to a one-year time-period so only minimal changes in symptom progression were observed on standardised measures of cognition and functional ability. Despite this, there was clear evidence of subjectively perceived symptom progression in participants' interview responses. In the future, researchers could examine the use of Twitter by people with dementia over a longer period of time to observe more substantial changes on standardised measures, and use a trajectory approach to longitudinal qualitative analysis (see Grosseohme & Lipstein, 2016). This approach would involve following individual participant trajectories to identify cognitive and functional ability factors that influence participants' use of Twitter. It should, however, be remembered that participants may withdraw from research studies as symptoms progress, which is what happened in this study.

The MMSE scores of participants tended to increase at follow-up, which is inconsistent with the progressive nature of dementia. The increase in MMSE scores

at follow-up, however, could reflect practice effects due to the frequent administration of this measure. Low MMSE scores on entry to the study could also be explained by the fatigue of two participants at the initial interview (P2, P5), anxiety about taking part in a new research project, measurement error (e.g. Feeney, Savva, O'Regan, King-Kallimanis, Cronin, Kenny, 2016), and one participant's low mood at the initial interview (P6). A measure of mood was not included in the design, but this could have influenced participants' MMSE scores and their use of Twitter. In the future, researchers could incorporate measures of mood in research examining the use of Twitter by people with dementia.

In this study, people with dementia were only asked about any changes in the content they posted on Twitter. An analysis of the content of their tweets was not included in the research design. In future research, a content analysis of tweets posted by participants could complement a longitudinal analysis and provide additional insights into how information posted by people with dementia changes over time.

The sample included in this study lacked diversity. Participants were relatively young, white British, and tended to have reasonably high socioeconomic status. Other groups of people with dementia (e.g. those who identify as ethnic, gender, or sexual minorities) may have different experiences of using Twitter, and this should be explored by researchers in the future. The snowball sampling strategy was also a limitation of the study. While this sampling technique was advantageous as it increased the size of the sample, it limited the sample to a group of people who knew each other offline and online. In addition, identifying account holders from the tweets posted by group dementia accounts might have limited the sample to advocates. In the future, researchers could also consider posting a tweet from their

personal profiles to recruit participants as this could potentially facilitate a more diverse sample. As the number of people with dementia increases, researchers could also consider using alternative methods to recruit participants such as contacting local groups for people with dementia.

The Twitter Analytics data collected in this study were also incomplete. This was due to changes in Twitter's API during the study, which only allowed collection of analytic information from the previous three months. In addition, there were technical difficulties accessing Twitter Analytics and one participant forgot his password. In the future, researchers should be aware of these issues and, where possible, it would be advisable to consider using commercial software that has to be purchased to access Twitter data; however, this will be costly as Twitter's premium package that uses the firehouse API and allows a user examine tweets posted beyond the past 30 days can cost up to \$1,899 per month (Twitter, n.d.). In addition, Twitter Analytics did not collect information about participants' monthly retweets which would have been useful in this study as some participants said they would often retweet information rather than post personal tweets when they were experiencing dementia-related difficulties. In the future, researchers could also consider using software which collects information about the number of retweets posted by participants.

Despite these limitations, this study is the first to examine changes in the use of Twitter by people with dementia over time, and highlights the willingness of people with dementia to continue using the platform and the importance of it in their lives despite self-reported symptom progression. This highlights the importance of platform developers working with people with cognitive disabilities to create online spaces that are dementia-friendly.

## **6.5 Conclusion**

In conclusion, the findings of this research suggest that the use of Twitter by people with dementia can vary according to the stage of the disease trajectory. While participants' dementia was stable across standardised measures of cognition and functional ability, they described increasing challenges of using Twitter over time. These findings suggest that Twitter might be valuable for people in the earlier stages of the disease and/or for those recently diagnosed, providing social connection and a pathway to advocacy. As people subjectively experience symptom progression, however, they may need to employ various strategies to continue using the platform. The findings of this research also suggest that when using Twitter becomes too difficult, people with dementia tweet less and eventually leave the platform. In the future, platform developers could consider working with people with dementia to make developments to Twitter to make it a dementia-friendly space.



## **Chapter 7**

### **Disciplinary Knowledge, Lived Experience, and Generational Differences: A Reflexive Statement**

## **7.1 Summary**

This chapter defines reflexivity and emphasises its importance in qualitative research. Critical reflections on the impact of my disciplinary background, lived experience, and personal characteristics on the research process are then presented.

## **7.2 Reflexivity**

Reflexivity is the process of critical self-reflection through which researchers consider their positionality (i.e. a person's stance in relation to the social and political context of the study; Coghlan & Brydon-Miller, 2014) and how it may impact the research process and outcomes (Bradbury-Jones, 2007; Guillemin & Gillam, 2004; Stronach, Garratt, Pearce, & Piper, 2007). Qualitative research is about finding meaning, and any meaning-making is context-bound, positioned, and situated (Braun & Clarke, 2019). In this sense, the researcher is an active instrument in the research process and any outcomes are the result of the collaboration between the researcher and participant (Pyett, 2003; Underwood, Satterthwait, & Bartlett, 2010). The concept of reflexivity therefore challenges the idea that knowledge production is objective and independent of the researcher producing it (Berger, 2015).

The aim of reflexivity is to improve the quality of research by helping the researcher to expand his/her understandings of how the positionality and interests of the researcher affect all stages of the research (Primeu, 2003). Reflexivity is important in qualitative research because it allows researchers to manage the values, knowledge, and biases that may affect the research process, thus enhancing the credibility of research by providing greater transparency about the researcher's

subjective role (Buckner, 2005; Cutcliffe, 2003; Gilgun, 2008; Macbeth, 2001).

Personal characteristics, lived experience, and the disciplinary background of a researcher can affect the way that he or she asks questions related to the research, uses language, and adopts lenses to make sense of data, which, in turn, shapes the findings and conclusions of the research (Berger, 2015; Kacen & Chaitlin, 2006).

It is clear that reflexivity is important in qualitative research to identify the researcher's centrality within the research, improve transparency, and, by extension, improve the credibility of the research. The following sections provide a critical reflection of my disciplinary background, lived experience, and personal characteristics which may have influenced the research process.

### **7.3 Disciplinary reflexivity**

My disciplinary background is in psychology, which I studied at undergraduate level. During my undergraduate degree I developed an interest in cyberpsychology, which is the study of the psychology of human-computer interactions (Krantz, 2019). I am particularly interested in social media and its impact on human behaviour. Public discussions of social media have tended to focus on the role of social media in exacerbating mental health problems and the negative role that this technology might be having on society (e.g. Johnson, 2019; Knox, 2019; Crawford, 2019). In contrast, there has been a recent movement within cyberpsychology that has challenged assumptions about the negative role of social media (e.g. Bell, Bishop, & Przybalski, 2015; Przybalski, 2019). With a focus on adolescents, researchers have used an open science framework and large sample sizes to show that the association between adolescent wellbeing and digital technology is negative but

small, thus challenging common beliefs about the impact of social media on this population (Orben & Przybylski, 2019).

I have aligned myself with this movement within cyberpsychology and brought these disciplinary understandings to my own research. Consequently, while I directly asked people with dementia about their negative experiences of using Twitter, I tended to focus on the value of social media for people with dementia and therefore might not have fully examined their negative experiences when collecting, analysing, interpreting, and reporting the data. It is worth noting, however, that although people with dementia mentioned some negative experiences of using Twitter, they were not forthcoming with this information (this will be discussed later in this chapter; see Section 7.4). I recognised my disciplinary bias when discussing the data with my supervisors who highlighted participants' negative experiences of Twitter which were evident in the data and had sometimes not been fully taken into consideration when I was interpreting and reporting the data. By sharing my data with more senior researchers with different disciplinary perspectives and experiences of using social media, I was able to reflect on my own disciplinary biases and undertake a more nuanced reading of the data.

I also tried to identify and challenge my disciplinary biases by adopting a teamwork approach to qualitative data analysis throughout my PhD. Researchers have argued that a teamwork approach to qualitative data analysis can improve the quality and rigor of methodological design, analysis, and interpretation (Barry, Britten, Barber, Bradley, and Stevenson, 1999). Throughout my PhD, I have taken my anonymised data to group data sessions (i.e. DataBee at the University of Exeter). DataBee is a group of PhD students and early career researchers who are interested in qualitative data analysis and often meet to analyse data together. It has

been theorised that multidisciplinary team analysis, in particular, can broaden possibilities in research by accessing researchers with more diverse training, assumptions, and knowledge bases (Opie, 1997). DataBee comprises researchers from diverse disciplines, including but not limited to psychology, sociology, education, human geography, and medical sciences. By sharing my data at these sessions, I was able to access the perspectives of people from different disciplines and examine different ways of reading the data, as well as challenge my own assumptions and theoretical lens.

Before doing my PhD, I had limited knowledge of qualitative research and I found the idea of conducting a qualitative analysis to be daunting. This was largely because my undergraduate psychology course focused on quantitative methods, which reflects teaching in most institutions where qualitative methods are often allocated little time on the curriculum and often taught after quantitative methods when students have developed assumptions about the value of scientific psychology (Clarke & Braun, 2013). Researchers have shown that graduate students experience isolation, uncertainty, and struggle with methods and methodology when using qualitative approaches to conduct research (Hunt, Mehta, & Chan, 2009), which reflects my experiences and the emotions I was feeling when I first started to engage with qualitative methods. DataBee, however, helped me to overcome these issues by providing me with a safe and supportive environment where I could develop my knowledge of qualitative methods, gain experience analysing data, learn from my peers, and, importantly, improve my confidence in my ability to analyse qualitative data. I therefore recommend that groups similar to DataBee should be established across all higher education institutions to ensure that postgraduate students who are

interested in qualitative research are properly supported at all stages of the research process.

Reflexivity and the emotional labour of conducting research are rarely considered in social media research ethical guidelines (Markham & Buchanan, 2012; British Psychological Society, 2017). This could be because of the 'distance' between the researcher and the subject when analysing publicly available data such as tweets. More recently, however, Hanna (2018) documented the emotional labour of conducting online research that examined men's experiences of infertility and argued for increased recognition of the importance of reflexivity in research that is conducted online. In my own research, I also felt the emotional labour when examining the tweets of people with dementia (Chapter 4). I did not feel 'detached' from the account holders because I was only examining tweets. In fact, I felt invested in their lives and often wondered how they were coping. I followed these account holders from my personal Twitter account and their tweets would often appear in my news feed. In this sense, I was part of the network I was studying and this connection to participants continued after data collection. It is also worth noting that I would often see the tweets of people with dementia outside of office hours and since I enjoyed using Twitter there was no real escape from my PhD research.

After Study Two (Chapter 4) was complete, one account holder stopped tweeting and I remember feeling concerned that her symptoms had progressed. After searching online, I found out that she had died. I remember feeling upset because even though I had not met this woman offline, I felt connected to her and her story. My experience of conducting social media research therefore reflects Hanna's (2018) experience. As well as analysing tweets, I interviewed people with dementia about their experiences of using Twitter, which added to the emotional labour of

conducting the research. Existing social media research ethical guidelines were not designed for research that is conducted with people, and the emotional aspects of conducting this research are not therefore considered. As social media research and related methods evolve, there is a need to update social media research ethical guidelines to consider the potential impact that the research could have on the researcher. This would ensure that appropriate risk assessments are completed and social media researchers receive adequate support (e.g. regular supervisory meetings, counselling) when conducting the research. It also creates space for the publication of critical and reflexive pieces, which are currently missing from the field (Cooky, Linabary, Corple, 2018; Hanna, 2018).

#### **7.4 Lived experience**

Before conducting this research, I had limited personal experience of dementia and could be seen as an 'outsider' within this field (Mullings, 1999). Not having lived experience can be beneficial in research with oppressed or marginalised groups as it identifies the participants as the experts, which can be an empowering experience (Berger, 2015). Berger and Rosenberg (2008), for example, found that mothers who experienced domestic abuse felt empowered, respected, and validated after being asked about their experiences by someone who was not a domestic abuse survivor. In my research, I found that participants discussed their experiences openly and were happy to answer any questions I had. These participants seemed enthused that someone wanted to listen to their experiences, which reflects a common experience among people with dementia who sometimes feel that their perspectives are dismissed (e.g. Alsawy, Tai, McEvoy, Mansell, 2019). My experience highlights

the value of research conducted with people with dementia as it validates their perspectives and situates them as experts.

Despite the potential benefits of not having lived experience of dementia, I did experience some challenges; for example, I found that participants would often focus on their positive experiences of using Twitter, rather than the negative. Personally, I found it difficult to ask participants about their difficulties, as I felt that I could never truly understand what it is like to have young-onset dementia and found it challenging to ask about the future because I was concerned about upsetting participants. I also found that participants were less willing to discuss their negative experiences, which could be because of age differences between participants and myself where they may have felt motivated to protect me. Participants also might not have fully disclosed their negative experiences because they were self-described advocates who wanted to challenge stereotypes and might have been concerned about my position as a researcher, as some professionals have publicly questioned the diagnosis and representativeness of dementia advocates (e.g. Howard, 2017).

I found that participants were particularly guarded about discussing their negative experiences in the initial interviews. By the six-month follow-up interviews, however, I had developed a rapport with participants, and they were more open about their negative experiences. This highlights the value of conducting repeat interviews, particularly with stigmatised groups as the researcher can develop a rapport with participants and thus improve the quantity and quality of data collected (Vincent, 2013). In the future, I would also recommend that researchers conduct focus groups with people with dementia to examine their negative experiences as participants might be more comfortable discussing their experiences with peers; however, this



will only be possible when the number of Twitter account holders with a diagnosis of dementia increases in size.

Studying the unfamiliar can also result in research findings not truly representing participants' experiences (Berger, 2015). When analysing the tweets of people with dementia in Study Two (Chapter Four), I was aware that my coding was directed by my own understandings and previous reading of literature on dementia advocacy, narrative, and the use of social media by people with other chronic health conditions (e.g. Bartlett, 2014a; Berry et al. 2017; Hemsley et al. 2015). This concern was particularly pertinent in Study Two (Chapter Four) because the voices of people with dementia were not represented in the data, only their tweets. I was therefore using my own understandings to guide the analysis and examine how people with dementia use Twitter. I overcame this issue by discussing the findings with a patient and public involvement group who advised on my research via email to confirm whether the findings were consistent with their experiences.

Patient and public involvement groups are not often discussed in social media research. The use of a patient and public involvement group in my research was beneficial as it ensured that my interpretation of the data was consistent with the group I was studying. Given that much of the social media research on health deals with complex and often stigmatised conditions (e.g. mental health, disability, sexuality), it is essential that researchers in the field engage with the considerable body of literature on patient and public involvement and include patient and public involvement groups at every stage of the research process.

The position of the researcher is fluid, rather than static, and inevitably changes throughout the research process (Eppley, 2006). During my research, I became more involved with the online community of people with dementia by tweeting about

dementia-related issues and using Twitter to publicly comment on stigmatising language, which is something I would not have done before conducting this research. In line with this, the majority of the participants in my research followed me on Twitter and would often share my tweets. In this sense, I felt that I went from being an outsider in dementia research to an ally of the dementia community. This continued connection was also beneficial for participants, who monitored my tweets to keep up-to-date on the progress of the research and any of its outputs.

In contrast, I often felt nervous about how participants would receive my work. Overall, however, my Study Two publication (see Chapter 4; Talbot et al.2020) was received positively by the community of people with dementia on Twitter. In fact, participants frequently tweeted links to the publication and spoke positively about their involvement in the study. Some participants also wrote blogs about the research and what it involved. Although participants mainly spoke positively about the research, the blogs and tweets of participants could be a useful resource for researchers to learn how their methods could be developed and their research skills (e.g. qualitative interviewing) could be improved in the future. In addition, my research was the topic of a '#DiverseAlz' Twitter chat whereby people with dementia, advocacy organisations, researchers, and carers tweeted about my research and their experiences of using Twitter. This provided further data on the use of Twitter by people with dementia and in the future questions could be posted on Twitter chats to access the perspectives of people with dementia.

The fact that participants publicly tweeted and blogged about their research experiences raises an important ethical issue as they compromised their anonymity; however, it was their decision to do this. While it should not be assumed that all account holders wish to be associated with their tweets, this finding reflects McKee's

(2013) assertion that sometimes people want to be associated with their social media posts, which is important to consider when making ethical decisions within social media research.

## **7.5 Generational Reflexivity**

In previous discussions of reflexivity, researchers have suggested that age differences between the researcher and participant can impact the research process. Underwood and colleagues (2010), for example, found that participants over the age of 70 gave shorter responses to questions from a younger researcher when compared with younger participants. In my research, I was initially concerned that the age difference between participants and myself might make it difficult for them to take me seriously as a researcher, engage with me, and openly discuss their experiences. I overcame this issue by taking the time to get to know participants when meeting them for the first time and explaining that I was there to learn from them. On reflection, however, the age differences between participants and myself did not seem to hinder data collection as participants spoke openly and at great length about their experiences of living with dementia and the role of Twitter. This could be because the sample in this research was relatively young, often took part in research with other PhD students, or were happy that someone was interested in their perspectives.

While age differences did not seem to inhibit the research process, I felt that other generational differences such as the amount of time using social media might have been more influential. I had my first Facebook account in 2009 when I was 14 (and a few years before this a Bebo account to connect with my friends), whereas the

participants in this research did not use social media until middle adulthood. As a result, there were clear distinctions between our different understandings and use of social media. Participants would often refer to my generation being different from theirs and using social media for more mundane purposes, which is illustrated by this quote from a participant in Study Three:

P9: *I'm a different generation to you...Your generation and even my kids, they tweet about what they have had for breakfast, what they are doing at lunchtime, and all the rest of it. And, to me that is a ton of bore. I would rather tell someone. My generation spoke to each other. We didn't have social media. So, we had to talk or write a letter*

This highlights that participants saw me as different to them and would assume that I used social media routinely and in a superficial manner. This diverted us from the topic we were discussing and sometimes caused tension between participants and myself, which could have hindered data collection. I overcame this issue by giving participants time to share their perspectives and using the interview guide to try and direct the conversation so that the focus was on how they used social media. On a few occasions, I found that it was beneficial to share aspects of my own experience with participants to develop rapport, such as how I used social media as an academic and how I recently taught my father to use social media. As mentioned in an earlier section of this chapter, focus groups could be conducted with people with dementia in the future to overcome generational differences and facilitate discussions between peers. People in the earlier stages of dementia could also be trained to be peer interviewers to overcome generational differences.

To take part in my research, participants were required to be active users of Twitter. As participants were active account holders, I assumed that we had a shared level of technical understanding and were both fluent in the 'language' of Twitter. In

reality, participants varied in their technical ability to use Twitter, ranging from people who only knew how to tweet and retweet to experts who used a range of functions that are available on Twitter. The range in technical ability became evident during interviews when I used Twitter-specific terminology, which resulted in some participants needing clarification. In the interview study, for example, one participant said *“I don’t understand the difference between this hashtag and @ thingy. I don’t know what the difference is”*. On occasion, this made me realise that participants and I did not have the same shared understanding, resulting in us sometimes speaking different technical languages and thus influencing the quality of data collected. Through this experience, I recognised that it is easy to assume that people have shared knowledge about social media terminology, which I will not take for granted in the future. I overcame this challenge by taking the time to explain what I meant when participants seemed confused or asked for clarification. In future research, it could be useful for researchers to develop a list of key terms that participants could use to check their understandings.

## **7.6 Conclusion**

In summary, my disciplinary knowledge about the impact of social media on human behaviour, lack of lived experience, exposure to participants’ accounts on Twitter, and generational differences in relation to the age at which we were first introduced to social media could have affected the research process. In the future, social media ethics guidelines could be updated with the aim of protecting the researcher. Focus groups could also be conducted with people with dementia as the number of Twitter

users with a diagnosis of dementia increases in size to overcome generational differences and encourage participants to speak about their negative experiences.

## **Chapter 8**

### **Discussion**

## **8.1 Summary**

This chapter provides an overview of the studies presented in this thesis. The findings of this research are discussed in relation to the wider literature on dementia advocacy and identity, illness narratives, and social media. Following this, the methodological and theoretical contributions are presented. The limitations of the thesis are then outlined, before considering the practical applications and future research directions of this research.

## **8.2 Overview of the research**

During the past 30 years, there has been a movement within dementia research that has recognised the importance of personhood, lived experience, and citizenship (Kitwood, 1993, 1997; Goldsmith, 1996; Bartlett, 2016; Bartlett et al. 2018). This movement provided a space for people with dementia to influence the research, practices, and policies that affect their lives. While this movement gained traction, social media was established and provided a new medium of communication. Social media has the potential to influence the experiences of people with dementia and support their social inclusion, by providing a pathway to advocacy and narrative. Twitter could be a particularly valuable tool for people with dementia because it has been used successfully by other oppressed and marginalised groups to encourage social change, but research on the use of Twitter by people with dementia is limited. The research presented in this thesis was the first to comprehensively analyse the use of Twitter by people with dementia and therefore represents a novel contribution to the field.



This thesis comprises three studies. Study One (Chapter 3) estimated the number of Twitter account holders who identified themselves as having a diagnosis of dementia, and examined their characteristics through an analysis of their profile descriptions. The findings of this study showed that people with dementia, with varying demographic characteristics and a range of diagnoses, used Twitter. The majority of account holders described themselves as 'living with' dementia, identified as dementia advocates, or were affiliated with working groups, suggesting they were using Twitter to facilitate an advocacy role. These account holders tended to be male and relatively young, indicating that there may be an underrepresentation of other groups of people with dementia on Twitter, such as older women.

Study Two (Chapter 4) explored how people with dementia used Twitter and, through a thematic analysis of their tweets, examined the illness narratives they created and promoted online. Six themes were generated through the analysis: nothing about us without us; collective action; experts by experience; living with dementia not suffering from it; community; and stories of dementia. People with dementia used Twitter to develop a collective identity to fight for representation, campaign, challenge stigma, educate others, and provide support. People with dementia also used Twitter to communicate their individual identities by documenting their lived experiences. These online narratives tended to focus on advocacy work and living well, rather than the negative aspects of living with dementia.

Study Three (Chapters 5 and 6) comprised cross-sectional and longitudinal analyses of case studies of people with dementia who used Twitter. Chapter 5 examined cross-sectionally how and why people with dementia used Twitter through an analysis of interview data. Six themes were generated through the analysis, which suggest that people with young-onset dementia used Twitter for social

connection, reminiscence, expanding their offline social networks, advocacy, and to enhance feelings of self-worth. While the use of Twitter by people with dementia was mainly positive, there were also some risks as some participants experienced technical difficulties and online abuse.

The longitudinal analysis (Chapter 6) aimed to identify how the use of Twitter by people with dementia changed over time. Three longitudinal themes were generated through the analysis: using Twitter more for advocacy; using Twitter becomes more demanding; and using Twitter less for social purposes. The findings of this study showed that Twitter might only be beneficial for people with dementia who have recently been diagnosed and/or are in the very early stages of the disease trajectory. As symptoms progress, it is likely that people with dementia will find the platform more difficult to use and eventually stop using the platform as a result. Some of the participants in this study used Twitter less for accessing support as they subjectively experienced symptom progression, suggesting that Twitter might not be an appropriate source of support for people with more advanced symptoms. Surprisingly, some participants used Twitter more for advocacy as they subjectively experienced advancing symptoms. For these participants, online advocacy served as a distraction that allowed them to focus on skills they had retained, despite symptom progression.

Overall, the findings from this thesis extend current understandings of living with dementia in the digital age. This research is important because social media are a ubiquitous part of human life, and it is likely that the number of Twitter account holders with dementia will increase when younger generations, who are more engaged with social media, age (Smith & Anderson, 2018). In the remaining sections of this chapter, the findings from all three studies are integrated and discussed

thematically in relation to the wider literature on dementia advocacy and identity, illness narratives, and social media. The methodological and theoretical contributions of the thesis are then outlined, before considering the limitations and practical applications of this research.

### **8.3. Dementia advocacy and identity**

People with dementia were traditionally thought to experience a loss of identity, abilities, and meaningful experiences; however, there has been substantial work since then that has challenged these views (Davis, 2004; Moore & Hollett, 2003). The findings of this thesis extend current understandings and challenge stereotypical beliefs about dementia by demonstrating that some people with dementia have the technical abilities required to use Twitter and are able to tweet in a coherent manner. By using Twitter in this way, the participants who took part in this research have shown that they are capable of communicating their lived experiences in a meaningful way, thereby reframing their condition as manageable disability, rather than a condition to be suffered and a living death (e.g. Fontana & Smith, 1989; Cohen & Eisdorfer, 1986; Woods, 1989).

Social models of dementia have emphasised that the social situation in which people with dementia find themselves is disabling (e.g. Kitwood, 1997; Sabat & Harré, 1992). In contrast, the findings of Study Two and Study Three (Chapter Four and Chapter Five) showed that the online social environment of Twitter enabled some people in the early stages of dementia to directly challenge stereotypes, educate others, and self-advocate. These participants used Twitter as a platform from which they could fight for social inclusion, and uphold the personhood and

citizenship status of those with a diagnosis. By using Twitter in this way, people with dementia might be able to change public perceptions and, in turn, reduce the malignant positioning of people with dementia (Sabat & Harré, 1992). This could improve the quality of life and everyday experiences of people with dementia.

Although the social environment of Twitter was mainly positive, some people with dementia received negative comments from other account holders containing stigmatising language (Chapter 5). This is problematic because researchers have previously shown that exposure to stigmatising comments can negatively affect a person with dementia and their sense of identity (Milne, 2010; Thornicroft, 2006). Some of the participants in this research also received tweets from other account holders publicly challenging their diagnosis, which reflects current public debates about the diagnoses of dementia advocates (e.g. Gordon, 2017). This finding was also consistent with Bartlett's (2014a) research, whereby advocates reported feeling oppressed by healthy others who expected them to behave in a typical way.

Although Twitter was a predominantly positive environment for people with dementia as it fostered a sense of community, provided a pathway to advocacy, and facilitated a sense of purpose (Chapter 4-6), it also replicated offline stigma and public debates. In this sense, Twitter cannot be considered an isolated space. Instead, it is situated within a greater social context that is shaped by attitudes and perceptions of dementia. This finding reflects a common understanding among researchers who study online behaviour that peoples' attitudes and offline experiences influence their online activities. For people with other chronic health conditions such as eating disorders, for example, researchers have found that people who score highly on measures of symptomology are more likely to seek out

online content that promotes disordered eating behaviours (e.g. Bachner-Melman et al. 2018).

A common finding across all three studies was the use of Twitter by people with dementia for advocacy. This mirrors Bartlett's (2014a) research, which found that dementia advocates connected with each other offline, developed a shared identity, and became politicised. The findings of this thesis extend current understandings by showing that some people with dementia used Twitter to develop an advocate identity, challenge stereotypes, raise awareness, educate others, lobby politicians, and fight for representation. For some people with dementia, Twitter provided a pathway to advocacy and was an important first step before getting involved in offline advocacy work (Chapter 5).

Online advocacy was beneficial for the people with dementia who took part in this research as it enabled them to construct a new identity at a time of perceived loss, which enhanced feelings of self-worth and distracted them from symptom progression (Chapter 5 and Chapter 6). This is also consistent with Bartlett's (2014a, 2014b) research, which showed that advocacy can be beneficial for people with dementia as it provides them with a new working role, anchors them in the present, and allows them to regain respect. The findings of this thesis extend Bartlett's (2014a, 2014b) findings by demonstrating that online advocacy can also be beneficial for people with dementia. In the future, people who are interested in advocacy and have recently been diagnosed with dementia could be encouraged to use Twitter to engage with established advocates and advocacy organisations.

Twitter was a valuable source of social connection and support for some of the people with dementia who participated in this research (Chapter 4 and Chapter 5). By facilitating social connection with people beyond their direct networks, Twitter

provided a platform through which some people with dementia could combat the 'shrinking world' that frequently accompanies a diagnosis (Duggan et al. 2008), thus making the experience of living with dementia less isolating. Despite this, some people with dementia did not use Twitter for social connection, suggesting that Twitter is not always an appropriate source of social connection for people with dementia. It is therefore important that people with dementia are able to access a variety of sources of social connection and choose what is most appropriate for them. While Twitter is not appropriate for all people with dementia, it is one resource that people with dementia could use for peer support and social connection.

Despite the potential of Twitter to facilitate social connection, it may only be appropriate for younger people or those in the earlier stages of dementia (Chapter 6). Other types of assistive technology might be more appropriate for people with more advanced symptoms. Group video cafés, for example, may be one option whereby appropriate facilitators could organise group calls for people with dementia using video calling software (e.g. Skype, Zoom). This would overcome some of the challenges that some participants reported in Study Three, such as difficulties with typing and coping with the pace of Twitter.

## **8.4 Narrative**

In recent years, people with dementia have communicated their experiences and perspectives by writing books (e.g. Mitchell, 2019), speaking at conferences, educating students about their lived experiences (Gilmour & Brannelly, 2010), and appearing in television programmes (David, 2016). Study Two and Study Three (Chapter 4 and Chapter 5) showed that some people with dementia have also used

Twitter to document their lived experiences and communicate their perspectives. With 68% of people now getting their news and information from social media (Shearer & Matsu, 2018), the use of Twitter by people with dementia might be increasing the visibility of their narratives, which could increase the likelihood of evoking social change.

Although people with dementia used Twitter to communicate their lived experiences, these tweets tended to be positively biased (Chapter 4 and Chapter 5). While a positive bias may be beneficial for people with dementia as it allows them to reject the role of a sick patient and position themselves as people who can live with the diagnosis (Sabat & Harré, 1992; Garden, 2010), it lead to a noticeable absence of narratives that depicted the challenges of living with dementia. This finding was also supported in the interview study (Chapter 5), whereby people with dementia reported using Twitter to present themselves in a positive manner, with the aim of giving hope to others with the diagnosis. Although a positive bias might be uplifting for some people with dementia, there is a risk that people who are struggling with the diagnosis might become disconnected from the Twitter community of people with dementia, compounding offline experiences of isolation. This dark side of the 'living well' agenda has also started to be recognised in research (e.g. Bartlett et al. 2017). In the future, researchers examining the tweets of people with dementia should be aware that these online narratives may be positively biased and not accurately reflect offline experience.

While the availability of Twitter means that the narratives of a great number of people with dementia can be shared, it does not necessarily mean a diverse range of experiences will be communicated. The findings of Study One (Chapter 3), for example, showed that account holders with dementia were more frequently young,

male, and self-reported advocates. Likewise, the findings of the longitudinal study (Chapter 6) suggest that only those in the earlier stages of dementia are active on Twitter. This demonstrates that only the narratives of a very specific group of people are represented on Twitter, the same select group whose narratives are represented offline (McParland et al. 2017). A lack of representation of the narratives of other groups of people with dementia, such as older women, could cause these people to continue to experience stigma and discrimination. While there has been a recent effort by researchers to engage with the narratives of underrepresented groups of people with dementia (e.g. Löf & Olaison, 2018; Regan, 2016), it is also important that the narratives of a more diverse group of people with dementia are represented in the public eye to raise awareness and challenge the stigma that these groups of people face. More work is therefore required by advocacy and non-profit organisations to ensure the voices of a more diverse group of people with dementia are heard.

## **8.5 Social media and other chronic health conditions**

There were several similarities between the use of Twitter by people with dementia and people with other chronic health conditions and disabilities. Similar to people with diabetes, cancer, mental health problems, and communication disabilities, people with dementia used Twitter to challenge stigma, access support, document experiences, fundraise, raise awareness, lobby politicians, and educate others (Chapters 4-6; Berry et al. 2017; Lachmar et al. 2017; Liu et al. 2016; Sugawara et al. 2012; Hemsley et al. 2015, 2018). Likewise, the use of Twitter by people with dementia focused on creating social change that improves the lives of



people with a diagnosis (Chapter 4 and Chapter 5), which was similar to the use of Twitter by people with cancer and diabetes to facilitate better medical care (Wicks, 2018; Granger, 2013).

The use of Twitter by people with dementia most resembled the use of Twitter by people with communication disabilities, who have used the platform to overcome challenges in offline communication and broadcast their perspectives, which might not otherwise be heard offline (Chapter 5; Hemsley et al. 2015, 2018; Hemsley & Palmer, 2016). Both communication disabilities and dementia are stigmatised disabilities, and the perspectives of these people have not traditionally been heard (Davis, 2004; Hemsley et al. 2015; Moore & Hollett, 2003). This suggests that Twitter might be a particularly valuable tool for people with stigmatised health conditions to raise awareness, challenge stigma, and communicate their experiences.

Comparative research could be conducted in the future, which considers the similarities and differences in the use of Twitter between groups of people living with different diagnoses.

It is also important to consider the extent to which the benefits and risks of using Twitter are specific to dementia. Firstly, after receiving a diagnosis, people with dementia can find themselves in a unique social situation in which they experience a loss of identity, a 'shrinking world', are assumed to be unable to take part in certain activities, and are associated with dementia-specific stereotypes that paint them as incompetent, sufferers, and victims (Duggan et al. 2008; Ryan et al. 2009; Spreadbury & Kipps, 2019). In contrast, the findings of this thesis show that Twitter can be valuable for people with dementia to counteract some of the challenges posed by the diagnosis, by facilitating advocacy, social connection and community membership, and enhanced feelings of self-worth.

Secondly, the people with dementia who participated in this research reported symptom progression which was specific to dementia and affected their ability to use Twitter (e.g. increased difficulties with concentration, reading, and typing). This finding also demonstrates that it is important for future researchers to consider the temporal aspects of social media usage, particularly among people with progressive health conditions. Thirdly, the dementia advocates who participated in this research encountered “*dementia doubters*” (see Chapter 5), a term which was co-constructed in an interview between myself and a participant to refer to Twitter account holders who publicly challenge the diagnoses of people with dementia. This is a risk specific to people with dementia, particularly dementia advocates who challenge the ‘sufferer’ narrative and demonstrate an ability to live with the diagnosis. By publicly evidencing life after a diagnosis of dementia, it is possible that some people with dementia will receive a backlash from other account holders for not presenting themselves in the typical way. While the research presented in this thesis focused specifically on Twitter, it is important to consider the extent to which the findings might apply to other forms of social media, particularly at a time when existing platforms are rapidly changing and new platforms are constantly being developed (Woodfield et al. 2013). Firstly, the use of Twitter by people with dementia for social connection may also be true for Facebook, as there are existing Facebook groups dedicated to facilitating peer support (e.g. The Young Onset Dementia Support Group; Craig & Strivens, 2016). In terms of advocacy, however, Twitter appears to be unique as it provided people with dementia direct access to the policymakers and practitioners who make decisions that affect their lives, and their tweets can potentially gain momentum (Chapter 4).

The short text nature of tweets is also unique to Twitter, which people with dementia said was beneficial as they found it easier to communicate in this format (Chapter 5). While it was not examined in this research, it is possible that people with dementia are also communicating through photographs, GIFs, emojis, and videos, to overcome challenges with typing. In the future, researchers could analyse the different types of content that are posted by people with dementia, identify whether people with dementia are using image-based platforms (e.g. Instagram) or video-sharing sites (e.g. YouTube), and determine the impact this is having on their lived experiences.

Profile descriptions and tweets were used in the analyses presented in Study One and Study Two (Chapter 3 and Chapter 4). While the use of social media data in these two studies provided valuable information about how people with dementia used Twitter, the interviews conducted with people with dementia (Chapters 5 and 6) provided additional information that was not evident in the Twitter data. In the interviews, participants discussed their negative experiences of using Twitter, the challenges they faced, and their reasons for using the platform, which could not have been identified in a study examining only social media data. Although Twitter data can be valuable for researchers who want to study online behaviour and access public perceptions, the findings of this research showed that research using only social media data does not facilitate a comprehensive understanding of behaviour. This finding is also reflected in research on the use of social media by people living with diverse health conditions (e.g. communication disabilities, depression), which have used additional techniques such as semi-structured interviews to understand how these groups of people use social media (e.g. Brunner et al. 2015, 2019; Hemsley et al. 2015; Radovic, Gmelin, Stein, Miller, 2017). In the future, researchers

who want to examine social media data should also consider using other complementary methods, such as semi-structured interviews and questionnaires, to develop more comprehensive understandings.

All of the participants who took part in Study Two and Study Three (Chapter Four and Chapter Five) were recruited via Twitter. Overall, account holders with a self-reported diagnosis of dementia were willing to take part in this research. This highlights that Twitter could be one viable method for researchers to recruit people with dementia to research, particularly as the number of Twitter users with dementia increases. However, it should be remembered that this approach to sampling may limit the sample to younger people with dementia and/or those in the earlier stages of the disease trajectory. This could result in older people with dementia and those with more advanced symptoms being excluded from research.

## **8.6 Methodological considerations and contributions**

As aforementioned, the aim of the longitudinal analysis was to examine changes in the use of Twitter by people with dementia (Chapter 6). This aim reflected an assumption that participants' cognitive and functional abilities would decline; however, there were no instances of substantial decline across participants and only one person stopped using Twitter altogether. In the future, researchers could use longer timeframes to increase the likelihood of identifying instances of substantial decline. This would allow researchers to map the participants' individual illness trajectories, which could then be aligned with their use of Twitter. This approach would provide a more comprehensive understanding of how the use of Twitter by people with dementia changes as symptoms progress.

Twitter Analytics were included in the design of Study Three (Chapter 6) to measure tweet frequency. During the study, changes were made to Twitter Analytics, which limited access to Twitter data from the previous three months only, resulting in a substantial amount of missing data. This reflects a widespread problem within social media research, whereby researchers are dependent upon the platforms they are studying still being relevant, and platform developers not making changes that could affect the research process (Weller, 2015). Consequently, it is important that social media researchers are flexible in their approach and responsive to change. If funding is available, researchers could consider using paid software in the future to access Twitter information.

The scroll back method was used in Study Three (Chapter 5 and Chapter 6; Robards & Lincoln, 2017) to encourage discussion about participants' use of Twitter. The scroll back method was originally included in the study design because it was expected that tweets would act as stimuli for memories, which would require recognition rather than free recall. In contrast, participants frequently would not remember posting their tweets or would discuss information that was not relevant to the research question. This finding contrasts with Robards and Lincoln's (2017) experience of using the scroll back method with young people, which enabled in-depth enquiry and allowed the researchers to examine rich life narratives. The use of the scroll back method in this research constitutes a novel contribution to the field by using this method with people with cognitive disabilities.

Despite the challenges of using the scroll back method with people with dementia, there were some cases where the scroll back method prompted interesting discussions, and it was particularly useful for participants who found it difficult to stay on topic. For these participants, examples of tweets gave them something tangible to

focus on. On reflection, it is advisable that future researchers ask participants to scroll through their tweets on a laptop or tablet device, and discuss which tweets they think are important. This would give participants more agency and potentially stimulate discussion that is more relevant.

As previously mentioned, Study Two (Chapter 4) was a thematic analysis of tweets. These tweets contained rich information about the lived experiences of people with dementia, their perspectives, and their use of Twitter. The findings of this thesis make a methodological contribution to the field by demonstrating that tweets combine over a period of time to create illness narratives, which can provide insight into lived experience.

## **8.7 Theoretical contributions**

Researchers have theorised that the persistence of identity among people with a diagnosis of dementia is evidenced through narrative, whereby narrative allows them to preserve, define, and update their identity (Ryan et al. 2009; Mills, 1997; Surr, 2006; Usita et al. 1998). The study of narrative identity in people with dementia was traditionally considered to be problematic as it is based on a person's ability to recall their experiences. The findings of this thesis, however, complement contemporary thinking about the persistence of narrative identity among people with dementia, despite their diagnosis (Ryan et al. 2009). In this research, narrative identity was evidenced through the tweets of people with dementia that documented their lived experiences and, when combined over time, formed an illness narrative.

A surprising finding of this research was that some people with dementia used Twitter to record their experiences and achievements so they could use them for

reminiscence in the future. By using Twitter in this way, people with dementia might be able to preserve aspects of their identities. In the future, social media posts could be integrated into reminiscence therapy, which has been shown to have positive short-term effects on cognition, quality of life, communication, and mood (O'Philbin et al. 2018). This would also provide people with dementia an increased sense of autonomy, as they would have control over which aspects of their identity are recorded and used for reminiscence.

Narrative theorists have argued that narrative provides a medium of communication through which people with health conditions or disabilities can reconstruct and communicate their identity (Garden, 2010). Ryan and colleagues (2009) have also theorised that people with dementia use writing to reclaim social identity. The findings of this thesis extend narrative models of identity in dementia by applying them to communication that takes place on Twitter. Through their use of Twitter, the participants in this research were able to reconstruct what it means to be a person with dementia, reject the suffering narrative, and reposition themselves as people with agency who could live with the diagnosis. Tweets appear to be another medium of communication that people with dementia can use to reaffirm their identities and facilitate social inclusion.

Narrative models of identity have been criticised for being limited to people with dementia who are able to communicate (Caddell & Clare, 2010). This is also true for the research presented in this thesis as it was limited to people with dementia who were still able to use Twitter. This research, however, raises questions about what constitutes a narrative. Firstly, the findings of the longitudinal analysis (Chapter 6) showed that some people with dementia retweeted more information as they subjectively experienced symptom progression. While this is problematic as retweets

are not composed using a person's own words, retweets allowed the participants in this research to continue to engage with Twitter and the combination of their retweets may constitute another form of narrative. The Twitter narratives of people with dementia also differed from other forms of narrative (e.g. books) as they were communicated in less than 280 characters. Researchers have theorised that tweets are the equivalent of 'short stories' that people tell about themselves (Page, 2012). The findings of Study Two and Study Three (Chapter 4 and Chapter 5) supported this idea by showing that people with dementia used to tweets document lived experience in small increments and when these tweets were combined, they can be considered to be a cumulative form of illness narrative.

The findings of this thesis also extend citizenship models of dementia (e.g. Bartlett, 2016; Bartlett et al. 2018) by showing that people with dementia have used Twitter to facilitate their social inclusion and further a social movement that is focused on improving the lives of those with a diagnosis. Dementia was clearly a political issue for participants, and Twitter provided some people with dementia an online space where they could enact their roles as active citizens, demonstrate agency, and influence the practices, policies, and attitudes that influenced their offline experiences. Citizenship models of dementia might, therefore, also need to consider the online spaces in which people with dementia reside and enact their roles as active citizens.

## **8.7 Limitations**

Although the research in this thesis presents a novel contribution to the field, there were some limitations. Firstly, the sample sizes across all three studies were



relatively small and the account holders were a very specific group of people (i.e. younger people in the earlier stages of dementia). Young-onset dementia is less common than late-onset with approximately 5% of people with dementia being diagnosed before the age of 65 (Prince et al. 2014). Consequently, the findings presented in this thesis cannot be applied to the majority of people with dementia. In the future, these findings may be more relevant to a larger number of people with dementia, particularly as younger generations age.

This research was also limited by the sampling technique for Study One (Chapter 3) that identified the population from which the majority of participants for Study Two and Study Three (Chapter 4-6) were recruited. Twitter's freely available Search Application Programming Interface (API) captures an estimated 74% of tweets (Ahmed & Bath, 2015). Free software can only provide a selection of tweets, never the full sample, so it is possible that potential participants were not located in the original searches and excluded from subsequent studies. In the future, paid software could be used to identify people with dementia on Twitter. The use of paid software was beyond the scope of a PhD research project as Twitter's premium package, which provides access to tweets posted beyond the past 30 days, can cost up to \$1,899 per month (Twitter, n.d.). Future researchers could consider recruiting participants from local groups for people with dementia. This will become an increasingly viable option as the population of Twitter users with dementia increases.

The samples included in this research also lacked diversity. Participants were predominantly white British, reasonably young, and tended to have reasonably high socioeconomic status. It is likely that other groups of people with dementia, such as ethnic, gender, and sexual minorities who face additional stigma (Adelman, 2016; Barret et al. 2015), have different experiences of using Twitter. In the future,

researchers could adopt an intersectional approach, and recruit more diverse samples to examine the experiences of different groups of people with dementia who use Twitter. It is worth noting, however, that participants were recruited from the population identified in Study One, and it is possible that people with dementia who use Twitter are predominantly a white group of people with relatively high socioeconomic status. This contrasts with the use of Twitter by oppressed and marginalised groups, whereby hashtags such as ‘#BlackLivesMatter’ have been used to facilitate discussions about racial inequalities and encourage social change (Highfield, 2016). In the future, researchers could examine this issue by identifying the characteristics that predict Twitter usage among people with dementia.

In Study One and Study Two (Chapter Three and Chapter Four), it was not possible to verify the diagnosis of account holders, which is a limitation of all research that uses social media data to examine chronic health conditions (e.g. Berry et al. 2017; Sugawara et al. 2012; Thomas, 2017). In addition, the cognitive scores of some participants in Study Three improved over time (Chapter 6), which is inconsistent with expectations given that dementia is a progressive condition characterised by cognitive decline (McKeith et al. 2017; McKhann et al. 2011). This might cause some people to question whether the participants in this research really have dementia, reflecting recent offline debates about the diagnoses of dementia advocates (e.g. Howard, 2017). Despite the fact that the cognitive scores of some participants improved over time, these participants still showed signs of overall impairment (Chapter 5 and Chapter 6). In addition, other factors might explain this marked improvement, such as measurement error, (Feeney et al. 2016), changes in mood (Anderson, Sachdev, Brodaty, Troller, & Andrews, 2007), fatigue and anxiety at the initial interview (Räihä, Isoaho, Ojanlatva, Viramo, Suklava, Kivelä, 2009), and

practice effects (Duff et al. 2007). Likewise, the symptoms of dementia can fluctuate over time and even within a single day (e.g. Bradshaw, Saling, Hopwood, Anderson, & Bodtmann, 2004), which might also explain changes in the MMSE scores. It is also possible that the measures of cognition and functional ability were not sensitive enough to identify symptom progression. In the future, researchers could examine the use of Twitter by people with dementia over a longer period of time to identify more substantial changes in cognition and functional ability, which might be identified on standardised measures.

## **8.8 Implications and future research directions**

Overall, the findings of this thesis suggest that Twitter could be a valuable tool for some people with dementia as it facilitates social connection, communication, and an enhanced sense of purpose (Chapter 4 and Chapter 5). A diagnosis of dementia can have a powerful effect on identity, causing a person to experience changes and/or losses in his or her perceived intellect, social contacts, and identity as a worker or parent (Spreadbury & Kipps, 2019; Griffin et al. 2015). Hence, Clinicians, non-profit organisations, and the friends and family of people with dementia could encourage people in the earlier stages of dementia to use Twitter to help them adjust to the diagnosis.

It is important, however, not to infer that the use of Twitter was an entirely positive experience for the people with dementia who participated in this research. There are risks involved and people with dementia can be vulnerable to receiving abusive comments online, they may have their diagnosis publicly challenged, and they may not connect with (or may be alienated by) the dominant 'living well' narrative

presented by other people with dementia who are prominent on Twitter. In the future, focus groups could be conducted with people with dementia to further explore how they overcome these challenges with the aim of developing helpful guidelines for people who are interested in using Twitter and have dementia. People with dementia, researchers, working groups, local groups, and national organisations could promote these guidelines. A recent emphasis has been placed on online safety where texts have been published advising internet users on how they can cope with trolling (e.g. Howard, 2018) and adopt more private and secure approaches to using the internet (e.g. Reeder, Ion, & Sonsolvo, 2017). The development of social media guidelines for people with dementia could not only provide people with dementia with information about how to use Twitter and make them aware of the risks of using this platform, but could also be used to promote their online safety.

The findings of Study Two and Study Three (Chapter Four and Chapter Five) showed that people with dementia used Twitter to educate others about lived experience, identifying themselves as experts by experience. As people with dementia are using Twitter in this way, researchers may be able to use Twitter as an efficient source of patient and public involvement. Researchers could contact the hosts of Twitter hashtag chats aimed at people with dementia (e.g. #AlzChat, #DiverseAlz) who could post questions about the research. Researchers could then use the responses of people with dementia to develop their research. This approach to patient and public involvement could be used to overcome challenges with the costs associated with engagement activities and getting people with dementia to travel to attend these activities (Bethell et al. 2018; Iliffe, McGrath, & Mitchell, 2011).

Despite the potential for Twitter to be a source of patient and public involvement, this approach might limit the group to younger people and/or those in the earlier

stages of dementia. This concern is also reflected in the literature on patient and public involvement that takes place offline, whereby researchers have experienced difficulties identifying representative individuals (both demographically as well as at different stages of dementia; Bethell et al. 2018). While using Twitter might provide one avenue for patient and public involvement, it might further perpetuate the concerns of researchers conducting offline patient and public involvement.

In Study Three (Chapter Five and Chapter Six), people with dementia experienced challenges when using Twitter, such as difficulties typing, problems concentrating, and finding the pace of Twitter overwhelming. Platform developers of Twitter could consider working with people with cognitive disabilities to create online spaces that are accessible for and inclusive of people with dementia. Suggestions for changes that could be made to Twitter to make it more dementia-friendly have been outlined in Chapter 6, but it might also be useful for focus groups to be conducted with people with dementia using visual examples of websites to facilitate discussions about features that might benefit people with dementia. Developing versions of Twitter that are more dementia-friendly could also benefit the developers of Twitter as it might result in a greater number of people using the platform. This would also further the 'tech for good' movement, which aims to develop technology that creates positive social change (e.g. Pal, 2017).

## 8.9 Conclusion

In conclusion, the findings of this thesis demonstrate that some people with young-onset dementia have used Twitter to identify themselves as advocates and people who can live *with* the diagnosis, thus challenging stereotypical assumptions about their abilities. This group of people has used Twitter to have a voice on the issues that affect them, create social change, educate others, establish new social connections, expand existing offline social networks, access peer support, document experiences, communicate, and enhance feelings of self-worth. While the use of Twitter by people with dementia was largely positive, the findings of this thesis show that there were some risks as the participants in these studies experienced technical difficulties and were vulnerable to online abuse. At present, Twitter might only be appropriate for younger people and/or those in earlier stages of dementia as people who subjectively reported symptom progression experienced difficulties using the platform and eventually stopped using it as a result. This thesis makes several methodological contributions to the field by using the scroll back method with people with dementia and showing that tweets combine over time to create illness narratives. In the future, researchers could work with platform developers to make Twitter more dementia-friendly, develop guidelines for people with dementia on how to use and be safe on Twitter, and use longer timeframes to further examine how the use of Twitter by people with dementia changes as symptoms progress.

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## **Appendices**

## Appendix A: Ethics certificate for Study One and Study Two.



### University of Exeter Medical School Research Ethics Committee

### Certificate of Ethical Approval

**Research Institute/Centre:** Institute of Health Services

**Title of Project:** Dementia, identity and the role of social media

**Name(s) of Project Research Team member(s):** Catherine Talbot, Dr Siobhan O'Dwyer, Professor Linda Clare and Dr Janet Heaton

**Project Contact Point:** Catherine Talbot

**This project has been approved for the period**

**From:** March 2017

**To:** October 2019

**University of Exeter Medical School**

**Research Ethics Committee approval reference:** Mar17/B/118

**Signature:**

A handwritten signature in black ink, appearing to read "R Garside".

**Date:** 17 March 2017

**Name of Chair**  
**Ruth Garside, PhD**

Your attention is drawn of the attached paper "Guidance for Researchers when Ethics Committee approval is given", which reminds the researcher of information that needs to be observed when Ethics Committee approval is given.

Application Reference Number 17/02/118

## Appendix B: Ethics certificate for Study Three.



### University of Exeter Medical School Research Ethics Committee

#### Certificate of Ethical Approval

**Research Institute/Centre:** Institute of Health Services

**Title of Project:** The Twitter use of people with Dementia: A Longitudinal Study

**Name(s) of Project Research Team member(s):** Catherine Talbot, Dr Siobhan O'Dwyer, Professor Linda Clare and Dr Janet Heaton

**Project Contact Point:** Catherine Talbot

**This project has been approved for the period**

**From:** 19 October 2017

**To:** 18 October 2019

**University of Exeter Medical School**

**Research Ethics Committee approval reference:** Oct17/B/126Δ1

**Signature:**

A handwritten signature in black ink, appearing to read "R Garside".

**Date:** 19 October 2017

**Name of Chair**  
**Ruth Garside, PhD**

Your attention is drawn of the attached paper "Guidance for Researchers when Ethics Committee approval is given", which reminds the researcher of information that needs to be observed when Ethics Committee approval is given.

Application Reference Number 17/06/126Δ1

## **Appendix C: Systematic search strategy for identifying Twitter account holders with a self-reported diagnosis of dementia.**

### **Statements of Having a Diagnosis**

“Living well”  
“Living with”  
“Person with”  
“Live with”  
“I have”  
“Diagnosed”  
“Diagnosis”  
“Suffer”  
“Patient”  
“Survivor”

### **Types of dementia**

“Dementia”  
“Alz”  
“PCA”  
“Posterior”  
“Logopenic”  
“Aphasia”  
“Frontal variant”  
“Frontal”  
“Alz”  
“Fvad”  
“Frontotemporal”  
“FTD”  
“Vascular”  
“VaD”  
“Infarct”  
“Subcortical”  
“Mixed”  
“Pick’s”  
“Picks”  
“Variant”  
“Semantic”  
“Behavioural”  
“Aphasia”  
“Lewy”  
“DLB”  
“corticobasal”  
“CBD”  
“Creutzfeldt”  
“CJD”  
“Neurocognitive”  
“Young” AND “onset”

“Early” AND “onset”  
“Young-onset”  
“Early-onset”  
“YOD”  
“EOD”  
“YOAD”  
“EOAD”

### **Groups of people with dementia**

“Working group”  
“Advisory”  
“Alliance”  
“DAI”  
“ADI”  
“EWGPWD”  
“EDWG”  
“3NDWG”  
“NIDWG”

## Appendix D: Study Two codebook.

Theme	Core Organising Concept	Description of Theme	Codes
Nothing about us without us	Representation	Using Twitter to fight for adequate representation of people with dementia in conversations about them.	<ul style="list-style-type: none"> <li>- Involving people with dementia in decisions about them.</li> <li>- Using Twitter to contribute to conference discussions.</li> <li>- Holding others accountable when people with dementia were not represented.</li> <li>- Praising account holders when people with dementia were involved in discussions about them.</li> </ul>
Collective Action	Collective acts	Using Twitter for fundraising, political lobbying, and raising awareness.	<ul style="list-style-type: none"> <li>- Sharing information about awareness events</li> <li>- Sponsored walks</li> <li>- Raising money for charities and organisations</li> <li>- Sharing petitions</li> <li>- Engaging with politicians</li> </ul>

Theme	Core Organising Concept	Description of Theme	Codes
Experts by experience	Education	Using Twitter to educate others about dementia.	<ul style="list-style-type: none"> <li>- Symptoms and diagnostic information.</li> <li>- Dementia-friendly communities.</li> <li>- Tips for interacting with a person with dementia.</li> <li>- Advice on how to care for a person with dementia.</li> <li>- Advice for healthcare professionals.</li> <li>- Advice for researchers.</li> </ul>
Stories of dementia	Narrative	Using Twitter to document experiences.	<ul style="list-style-type: none"> <li>- Achievements.</li> <li>- Advocacy work.</li> <li>- Taking part in research.</li> <li>- Passing a driving assessment.</li> <li>- Negative experiences</li> <li>- Other forms of social media to document experiences.</li> </ul>



Theme	Core Organising Concept	Description of Theme	Codes
Living with dementia, not suffering from it	Stigma	Using Twitter to challenge stigma and dementia stereotypes.	<ul style="list-style-type: none"> <li>- Tweets about stereotypes</li> <li>- Making comparisons with other health conditions.</li> <li>- Challenging stereotypes</li> <li>- Discussing the role of language.</li> <li>- Providing suggestions for appropriate language.</li> <li>- Holding others accountable.</li> </ul>
Community	Support	Using Twitter to support other account holders.	<ul style="list-style-type: none"> <li>- Directly supporting other people with dementia.</li> <li>- Tweeting about offline sources of support for people with dementia.</li> <li>- Twitter as a source of support.</li> <li>- Supporting carers.</li> </ul>

## Appendix E: Information sheet for Study Three.



### **The Twitter Use of People Living with Dementia: A Longitudinal Study INFORMATION SHEET FOR PARTICIPANTS VERSION NUMBER [ 6 ] : DATE [ 07/02/2018 ]**

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate.

#### **Why me?**

We are interested in people with dementia who are using Twitter. As you are active on Twitter and have publicly identified as having dementia in your profile, we would like you to take part in this study.

#### **Who will be conducting this research?**



Catherine Talbot is a PhD student at the University of Exeter. Catherine will be conducting the interviews and should be the first person you contact if you have any questions or concerns. You can contact Catherine on 01392 725 927 or [ct500@exeter.ac.uk](mailto:ct500@exeter.ac.uk)

Dr Siobhan O'Dwyer, Professor Linda Clare, and Dr Janet Heaton will be supervising this project. Siobhan is Catherine's first supervisor and can be contacted via email ([S.ODwyer@exeter.ac.uk](mailto:S.ODwyer@exeter.ac.uk)) if you are unable to contact Catherine.

#### **Why are we doing this research?**

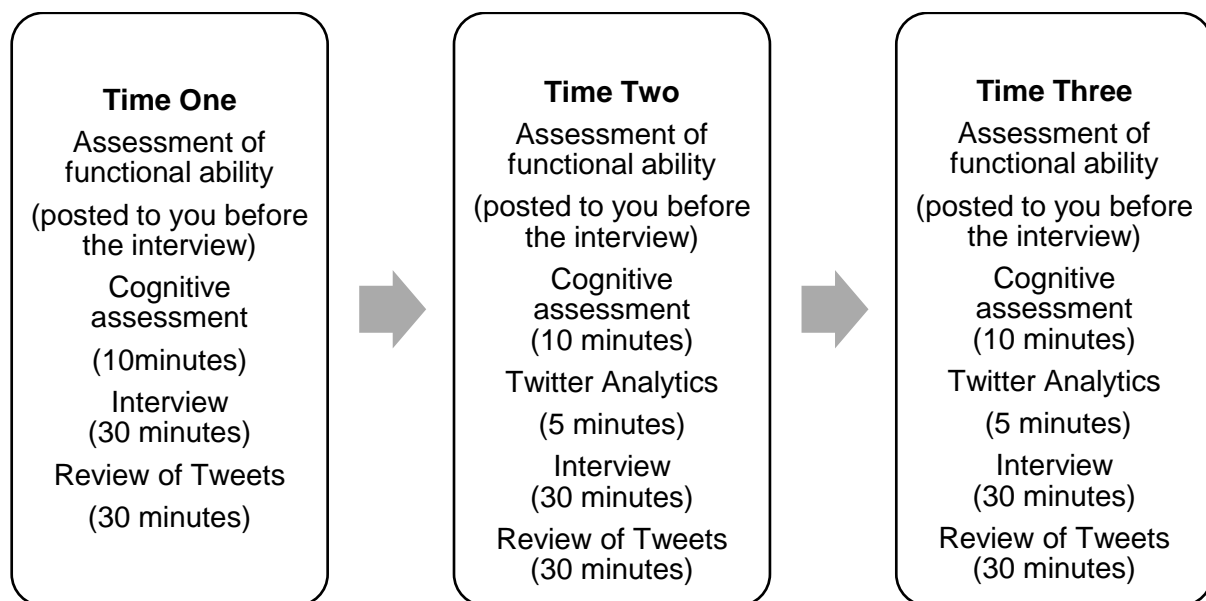
This project will explore how and why people with dementia use Twitter, and how this changes as the symptoms of dementia progresses. This project is being undertaken as part of a PhD in Medical Studies

#### **What will happen if I participate?**

You will be asked to take part in three one-on-one interviews across the period of one year. These interviews will last approximately 60 minutes. We ask that the interviews take place face-to-face, this can either be in your home or in a public place. As part of the interviews, you will be asked to scroll through your tweets and discuss them with Catherine. Structured breaks will be offered during meetings, and as needed.

For the purposes of publishing this study we would like to assess aspects of functional ability and cognition. The assessments of functional ability will be sent to your home address for you to complete and send back to us using a pre-paid postage envelope. The assessment of cognition will take approximately 10 minutes to complete and will take place before each interview. Before interviews two and three, we would also like to look at some of your Twitter data (e.g. number of followers, number following, tweet frequency, etc.). Catherine will access this using <https://analytics.twitter.com>.

The figure below shows what each meeting will involve.



This study involves a semi-structured questioning technique where some questions have been determined in advance, but others will be guided by your responses during the interview. Consequently, although the Medical School Research Ethics Committee is aware of the general topics to be explored in the interview, the Committee has not been able to review all the questions that will be asked.

### **Can I change my mind and withdraw from the project?**

If you decide to take part, you may withdraw from the project at any time. To withdraw from the study please contact Catherine, either by telephone or email. You will not be required to provide an explanation for wanting to withdraw from the study.

### **Do I have to give consent before I participate?**

If you wish to be involved in this project, it is important that you give consent. To consent to take part in this study please fill out and return the attached consent form to Catherine, either by email or post. If you would like to post this back to us, please contact Catherine so she can send you a pre-paid return envelope.

### **What are the risks associated with participating in this research?**

During the interviews, you may find it upsetting to reflect on past experiences or you may become tired. You are not obliged to answer all of the questions and can stop the interview process at any time. If you feel you are unable to continue the interview at any point please let Catherine know.

### **Will my responses be private and confidential?**

Any information collected from participants will remain anonymous and no personal information or identifying details will be released. All data will be stored on a password protected computer for 5 years. After 5 years, the data will be destroyed.

The only situation in which we might need to share information about you with other professionals would be if the researchers observe or hear anything that causes very serious concern about your or someone else's health, safety, or well-being. If this happens the researchers have a duty to inform an appropriate professional, such as your GP or social worker. We would make every effort to explain to you why we need to share this information before doing so.

### **What will the researchers do with my information?**

The results will be published in academic journals and presented at academic conferences. Catherine will disseminate the research via her Twitter account (@Catherinetalb) and blog (blogofasocialmediaresearcher.wordpress.com), both of which are used in a professional capacity. The findings will also be disseminated in the form of press releases. Any reported information will be removed of any identifiable markers. All participants will be provided with a summary of the research findings.

### **What if I have any questions?**

If you have any questions about our project, either now or in the future, please feel free to contact Catherine Talbot either via email ([ct500@exeter.ac.uk](mailto:ct500@exeter.ac.uk)).

### **Complaints**

If you have any complaints about the way in which this study has been carried out please contact the Chair of the University of Exeter Medical School Research Ethics Committee:-

Ruth Garside, PhD  
Chair of the UEMS Research Ethics Committee  
Email: [uemsethics@exeter.ac.uk](mailto:uemsethics@exeter.ac.uk)

## Appendix F: Consent form for Study Three.



### The Twitter Use of People Living with Dementia: A Longitudinal Study CONSENT FORM FOR PARTICIPANTS VERSION NUMBER [ 6 ] : DATE [ 07/02/2018 ]

I have read the Information Sheet Version Number [ 6 ] Dated [ 07/02/2018 ] concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

#### I know that:

		<i>Please circle</i> Yes / No
1.	My participation in the project is entirely voluntary;	Yes / No
2.	I have read and understand the information sheet for this study and I have had the opportunity to ask questions about the study.	Yes / No
3.	I am free to withdraw from the project at any time without any disadvantage;	Yes / No
4.	The data [audio-tapes] will be retained in secure storage;	Yes / No
5.	I am free to decline to answer any particular question(s).	Yes / No
6.	I agree to take part in the cognitive assessment and assessment of daily functioning	Yes / No
7.	I am free to take a break from the interview process or withdraw from the study if I feel any discomfort.	Yes / No
8.	The results of the project will be published but my anonymity will be preserved.	Yes / No
9.	I understand that my contact address will be shared with someone at Exeter University for the purpose of ensuring Catherine Talbot's safety	Yes/No
10.	I understand that if the researchers hear or observe anything that causes serious concern about my or someone else's health, safety or well-being, they have a duty to inform my GP or another appropriate professional.	Yes/No

**Contact information**

<b>Name:</b>	
<b>Contact address:</b>	
<b>Contact telephone number:</b>	
<b>Email address:</b>	

**Next of kin**

<b>Name:</b>	
<b>Contact address:</b>	
<b>Contact telephone number:</b>	

**GP contact information**

<b>Name of GP</b>	
<b>GP address</b>	
<b>GP telephone number</b>	

**I agree to take part in this project.**

.....  
(Printed name of participant)

.....  
(Signature of participant)

.....  
(Date)

.....  
(Printed name of researcher)

.....  
(Signature of researcher)

.....  
(Date)

**This project has been reviewed and approved by the University of Exeter  
Medical School Research Ethics Committee  
UEMS REC REFERENCE NUMBER: 17/06/126Δ2 (CA251)**

## Appendix G: Demographic form for Study Three.



### The use of Twitter by People Living with Dementia: Participant Details

**Name:** \_\_\_\_\_

**Age of participant at start of study:** \_\_\_\_\_

**Sex:** Man/ Woman

**Ethnicity:** \_\_\_\_\_

**Highest level of education:** \_\_\_\_\_

**Current state of employment:** ☐ Employed  
☐ Self-employed  
☐ Retired  
☐ Unemployed

**If employed, what is the full title of your main job?**

\_\_\_\_\_

**If retired, what was the full title of your main job?**

\_\_\_\_\_

**If unemployed, what was the full title of your last main job?**

\_\_\_\_\_



- Diagnosis:** ☐ Alzheimer's disease  
☐ Frontotemporal dementia  
☐ Vascular dementia  
☐ Dementia with Lewy bodies

Other (Please specify): \_\_\_\_\_

**Age at Diagnosis:** \_\_\_\_\_

## Appendix H: Capacity checklist.

### CENTRE FOR RESEARCH IN AGEING AND COGNITIVE HEALTH

#### DEMONSTRATION OF CAPACITY: CHECKIST FOR RESEARCHER TAKING CONSENT FROM PARTICIPANTS WITH EARLY-STAGE DEMENTIA OR MILD COGNITIVE IMPAIRMENT

The Mental Capacity Act proposes that people should be assumed to have capacity unless otherwise demonstrated. People with early-stage dementia or mild cognitive impairment are normally expected to have capacity to give informed consent to research participation. Capacity in this sense is demonstrated by the ability to understand and retain the information given about the research, to weigh up that information in order to reach a decision, and to state a decision clearly. The following checklist should be used when seeking informed consent from such individuals to ensure that these aspects are evaluated and that the criteria for capacity are met. If there is any doubt about capacity then consent must not be taken.

Study:

Participant ID:

Ability	Examples of how ability may be demonstrated	Ability demonstrated? (yes/no)	Comments and notes
Understanding the information given about the research	Describing what the study involves. Asking appropriate questions. Seeking clarification.		
Retaining the information given about the research	Referring back to information given earlier in the meeting. Referring to the information sheet.		
Weighing up the information to reach a decision	Identifying advantages of participating or concerns about participating. Asking relevant questions. Discussing the information with a third party e.g. a family member.		
Communicating a clear decision	Giving a clear and unambiguous indication of willingness to take part.		

Researcher name:

Signature:

Date:

## Appendix I: Self-rated version of the Independent Activities of Daily Living Scale.

### Instrumental Activities of Daily Living (Self-Rated version)

For each question, circle the points for the answer that best applies to your situation

1. Can you use the telephone?

Without help \_\_\_\_\_ 3

With some help \_\_\_\_\_ 2

Completely unable to use the telephone \_\_\_\_\_ 1

2. Can you get to places that are out of walking distance?

Without help \_\_\_\_\_ 3

With some help \_\_\_\_\_ 2

Completely unable to travel unless special arrangements are made \_\_\_\_\_ 1

3. Can you go shopping for groceries?

Without help \_\_\_\_\_ 3

With some help \_\_\_\_\_ 2

Completely unable to do any shopping \_\_\_\_\_ 1

4. Can you prepare your own meals?

Without help \_\_\_\_\_ 3

With some help \_\_\_\_\_ 2

Completely unable to prepare any meals \_\_\_\_\_ 1

5. Can you do your own housework?

Without any help \_\_\_\_\_ 3

With some help \_\_\_\_\_ 2

Completely unable to do any housework \_\_\_\_\_ 1

6. Can you do your own handyman work?
- Without help\_\_\_\_\_3
- With some help\_\_\_\_\_2
- Completely unable to do any handyman work\_\_\_\_\_1
7. Can you do your own laundry?
- Without help\_\_\_\_\_3
- With some help\_\_\_\_\_2
- Completely unable to do any laundry at all\_\_\_\_\_1
- 8a. Do you take any medicines or use any medications?
- Yes (If “yes”, answer question 8b.)\_\_\_\_\_1
- No (If “no”, answer question 8c.)\_\_\_\_\_2
- 8b. Do you take your own medicine?
- Without help (in the right doses at the right time)\_\_\_\_\_3
- With some help (take medicine if someone prepares it for you and/or reminds you to take it)  
\_\_\_\_\_2
- Completely unable to take own medicine\_\_\_\_\_1
- 8c. If you had to take medicine, could you do it?
- Without help (in the right doses at the right time)\_\_\_\_\_3
- With some help (take medicine if someone prepares it for you and/or reminds you to take it)  
\_\_\_\_\_2
- Completely unable to take own medicine\_\_\_\_\_1
9. Can you manage your own money?
- Without help\_\_\_\_\_3
- With some help\_\_\_\_\_2
- Completely unable to handle money\_\_\_\_\_1

## Appendix J: Study Three interview schedule for the initial interviews.

1. Can you tell me about when you first decided to use Twitter? *Prompt: Why did you first join Twitter?*
2. Did you use Twitter before receiving a diagnosis of Dementia? *Prompt: How did your tweeting change after receiving a diagnosis?*
3. Why did you decide to tell people on Twitter that you have dementia? *Prompt: What reaction did you get from other account holders?*
4. What are your main reasons for using Twitter? *Prompt: why do you use Twitter in this way?*
5. Can you tell me about what you choose to tweet? *Prompt: Why do you post that on Twitter? Is there anything you wouldn't post on Twitter?*
6. Can you tell me about any problems you have experienced when using Twitter? *e.g. have people not been nice to you, issues with security, difficulties with the platform itself.*
7. Have you received any negative responses from other account holders because of your diagnosis? *Prompt: How did that make you feel? How did you respond to this?*
8. Do you tweet about your experiences of living with dementia? *Prompt: Why/Why not? What reactions do those tweets get from other account holders?*
9. Can you tell me about any positive experiences you have had when using Twitter?

**\*Show participant printout of Twitter bio\***

10. I have printed off your Twitter bio, could you tell me why you have included this information in your Twitter profile?

11. Do you think you present yourself differently on Twitter compared to offline?

*Prompt: Could you tell me a bit more about that?*

12. Can you tell me about who you interact with on Twitter? *Prompt: do you interact with other people with dementia on Twitter? Why? What do you tweet each other? How do they make you feel? Have you met them offline? Are there any other people you interact with on Twitter?*

13. How do you expect to use Twitter in the future? *Prompt: do you think it will change over time*

**Appendix K: Study Three interview schedule for six-month follow-up interviews.**

1. Is there anything you would like to tell me about your use of Twitter before I begin my questions?
2. Did anything change in your use of Twitter after our interview six months ago?  
*Prompt: What changed? How/Why are you using Twitter differently?*
3. Have you experienced any changes in your dementia since we met six months ago? *Prompt: What aspects are causing you concern? How has it influenced your use of Twitter?*
4. Do you think you will use Twitter differently if your dementia becomes more difficult? *Prompt: What actions will you take to continue using Twitter? How will you feel if you are unable to use Twitter?*
5. Can you tell me about the support you receive for your dementia? *Prompt: Has the support you receive changed during the past six months? How does Twitter fit in with this?*
6. At our last meeting, you said that you used Twitter for these reasons: **\*insert examples from previous interview\***. Has this changed over the past six months? *Prompt: Why has it changed?*
7. Do you think your tweets are having an impact? *Prompt: What impact are they having? Are they having a national or local impact? How does this make you feel? Is this the impact that you intended to have?*
8. Is there anyone who helps you to use Twitter? *Prompt: Can you tell me a bit more about this?*

9. Is there an overall message that you are trying to tell through your tweets?  
*Prompt: Are your tweets separate stories or do they all link together? What message are you trying to share? Why? What response are you getting back?*
10. There are positive and negative aspects of living with dementia, what do you focus on in your tweets? *Prompt: why? Will this change?*
11. **\*Discuss participant's Twitter bio if this has changed since the previous interview\***
12. Can you tell me about any other social media platforms you use? *Prompt: Do you use Facebook? Do you blog? Why do you use these platforms? Which do you prefer?*
13. What do you post on Facebook/blogs in comparison to Twitter? *Prompt: Why don't you post this on Twitter? Are there any other differences?*
14. Do you connect with different people on Facebook than on Twitter? *Prompt: who? Why don't you connect with these people on Twitter?*



## Appendix L: Study Three interview schedule for 12-month follow-up interviews.

1. Is it okay for me to start by asking if you or those closest to you have noticed any changes in your dementia recently? *Prompt: What aspects are causing you concern? Has this influenced your use of Twitter? How?*
2. At our last meeting, you said that you used Twitter for these reasons: **\*include examples here\***; is this still the case or has your use of Twitter changed? *Prompt: Why has it changed?*
3. What devices do you use to access Twitter? *Prompt: do you prefer a particular device? Why? Have you switched devices while taking part in this study?*
4. At our last meeting, you said that you used Twitter to tell this type of message **\*include example here\***. Do you still promote **\*example\*** on Twitter or has this changed recently? *Prompt: Why has this changed?*
5. At our last meeting, you told me that you tend to tweet about **the positive/positive and negative aspects** of your life; is this still the case or has this changed recently? *Prompt: Why has this changed?*
6. Can you tell me about any problems you have experienced when using Twitter since we met six months ago? *Prompt: Have you had any difficulties using the platform itself? Have people not been very nice to you on Twitter?*
7. Some people have used Twitter to question whether some dementia advocates really do have dementia. Is this something you have experienced on Twitter? *Prompt: How does this make you feel?*
8. **\*Discuss the participant's Twitter bio if this has changed since the previous interview\***

9. Some participants have said that Twitter was a valuable source of social connection for them after they received their diagnosis; do you think more people with dementia should be encouraged to use Twitter? *Prompt: Why? Who should encourage people with dementia to use Twitter?*
10. What advice would you give to people who design and run Twitter to make it more accessible for people with dementia? *Prompt: Why is that important?*
11. What advice would you give to another person with dementia about using Twitter? *Prompt: Why is that important?*
12. As you are aware, this is our last interview. Do you think taking part in this study has influenced your use of Twitter? *Prompt: How has it influenced your use of Twitter?*
13. Finally, could you briefly summarise what you think the advantages and disadvantages of being on Twitter have been for you?

**Appendix M: An example of how tweets were presented to participants in the scroll back section of Study Three.**



## Appendix N: Interview study codebook.

Theme	Core organising concept	Description of theme	Codes
Using Twitter for community.	Social connection.	Using Twitter for social connection and peer support.	<ul style="list-style-type: none"> <li>- Feelings of isolation and loss of identity after diagnosis.</li> <li>- Lack of post-diagnostic support.</li> <li>- Accessing peer support on Twitter.</li> <li>- Making friends.</li> <li>- Keeping in touch with friends and advocacy groups.</li> <li>- Giving support to other account holders.</li> <li>- Twitter is a lifeline.</li> <li>- Feeling connected as a result of being active on Twitter.</li> <li>- Using Twitter to combat feelings of isolation.</li> </ul>
Using Twitter for expression.	Self-expression.	Using Twitter to overcome challenges in offline communication.	<ul style="list-style-type: none"> <li>- Twitter is easier than face-to-face communication.</li> <li>- Family and friends are not on Twitter.</li> <li>- Tweeting is therapeutic.</li> <li>- Character limit of tweets.</li> <li>- Experiencing trolling as a result of speaking openly about experiences.</li> <li>- Difficulties tweeting.</li> </ul>

Theme	Core organising concept	Description of theme	Codes
Using Twitter as a diary.	Reminiscence.	Using Twitter to document achievements and experiences to look back at them in the future.	<ul style="list-style-type: none"> <li>- Recording experiences.</li> <li>- Documenting experiences because of memory difficulties.</li> <li>- 'Memories' function.</li> </ul>
Using Twitter as a soapbox.	Advocacy	Using Twitter to engage in advocacy work.	<ul style="list-style-type: none"> <li>- Challenging stigma.</li> <li>- Normalising dementia.</li> <li>- Campaigning.</li> <li>- Raising awareness.</li> <li>- Reaching a wider audience.</li> <li>- Holding others accountable.</li> <li>- Dementia doubters.</li> <li>- Advocacy is unique to Twitter.</li> </ul>
Using Twitter as a springboard.	Offline environment.	Using Twitter to increase offline social connections and access information about offline activities.	<ul style="list-style-type: none"> <li>- Accessing information about offline events.</li> <li>- Would not know about offline events without Twitter.</li> <li>- Becoming involved in offline advocacy work because of Twitter.</li> <li>- Making new friends offline as a result of using Twitter.</li> </ul>

Theme	Core organising concept	Description of theme	Codes
Using Twitter to enhance self-worth.	Sense of purpose.	Using Twitter to maintain a sense of purpose.	<ul style="list-style-type: none"> <li>- Feeling valued after experiencing a loss of identity.</li> <li>- Helping others on Twitter to enhance feelings of self-worth.</li> <li>- Fighting for social change on Twitter to foster a sense of purpose.</li> <li>- Finding purpose from educating others about dementia on Twitter.</li> </ul>

## Appendix O: Example Participant Matrix

Themes	Baseline	Six month follow-up	Twelve month follow-up
Difficult to concentrate on Twitter.	P10 likes using Twitter and uses it every day. He finds Twitter “ <i>fast moving</i> ”. He does not think the fast moving nature of Twitter is a bad thing as it keeps him “ <i>a little bit sharp</i> ”.	P10 reports using Twitter less because he finds it difficult to concentrate. “ <i>I suppose I just can’t concentrate on it for any length of time. That’s the same as watching television, it’s difficult to focus and follow a plot on television so it’s difficult to follow a plot on anything really. So, I think it’s that focus on one thing for any length of time is just becoming more difficult I suppose really.</i> ”	P10 has stopped using Twitter as he finds it difficult to use the platform and process all of the information. “ <i>I think personally I think things have become more difficult for me to use social media. The amount of information I seem to absorb changes or the ability to have that information changes and I guess that it becomes hard work and I think “oh you know what I can’t really be bothered.”</i> ”

Themes	Baseline	Six month follow-up	Twelve month follow-up
Social connection	Twitter is a valuable source of social connection for P10. He likes having the <i>“world at his fingertips”</i> .	P10 still uses Twitter to connect with friends, but is concerned that he would not be able to communicate with these people on a regular basis if he was unable to use Twitter. <i>“It’s good to have a connection and in actual fact it’s quite good to have a connection with a lot of people who only use Twitter and not Facebook, so if I didn’t use Twitter I wouldn’t communicate with those people on a regular basis. So, not good”</i>	Since P10 has stopped using Twitter, he is no longer in contact with some of his friends. <i>“Those that are not on Facebook that are just on Twitter, I haven’t had any communication with them since probably well before Christmas maybe.”</i>



**Appendix P: Example longitudinal matrix.**

Themes	P1	P2	P3
Using Twitter becomes more demanding	No change in P1's ability to use Twitter.	No change in P2's ability to use Twitter.	P3 finds composing tweets more difficult. Twitter is particularly difficult to use after an update. This participants reports taking more breaks from Twitter at 12-month follow-up.
Using Twitter less for social purposes	P1 stops using Twitter for social connection and interaction with dementia advocates at 12-month follow-up.	P2 continues to use Twitter to connect with other people.	P3 continues to use Twitter to connect with friends and make new social contacts.
Using Twitter more for advocacy	P1 continues to use Twitter for campaigning, raising awareness, and making organisations aware of practices that are not dementia-friendly.	P2 tweets more about campaigning and wants to use Twitter to influence policymaking and public attitudes towards dementia.	P3 continues to use Twitter for campaigning, challenging stigma, and raising awareness.

